THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

AUG 17 1994

The Honorable Albert Gore, Jr.
President of the Senate
Washington, D.C. 20510

Dear Mr. President:

I am submitting the report "High Cost Hospice Care" in response to section 6016 of the Omnibus Budget Reconciliation Act of 1989, P.L. 101-239.

BACKGROUND

Section 6016 of P.L. 101-239 mandates the conduct of:

> "(1) . . . a study of high cost hospice care provided to Medicare beneficiaries under the Medicare program, and . . . [an evaluation of] the ability of hospice programs participating in the Medicare program to provide such high cost care to such patients; and (2) based on such study, . . . [the development of] methods to compensate such programs for providing such high cost care."

In order to implement this charge, an effort was undertaken by the Health Care Financing Administration (HCFA) to clarify the intent of the legislative language and to identify the nature and magnitude of the perceived problem since high cost care can be defined several ways, most of which are not financially problematic within the existing reimbursement mechanism. At the start of the study, hospice representatives indicated that most of the expensive hospice patients were those with difficult or uncontrollable pain. Therefore, much of the focus of the subsequent literature search and the composition of the clinical panel was in the direction of the state of the art in pain management.

HCFA consulted with representatives of the hospice industry, convened a panel of clinical experts, surveyed the clinical literature, analyzed data provided by hospices on patients who used high cost treatments or were otherwise defined by the hospice as high cost, and analyzed Medicare beneficiary hospice enrollment and utilization of hospice and other Part A and Part B services.

REPORT OVERVIEW

The literature review and the clinical advisors identified similar types of infrequently used interventions that could result in high costs. The infrequency of these interventions was confirmed by the analysis of high cost cases submitted by hospices in response to the survey conducted by the National Hospice Organization. Most of the high cost cases identified in the survey were more likely to have unusually long lengths of stay rather than have received atypically costly interventions. An analysis of the Medicare claims data shows that the longest lived hospice patients, in fact, were the least expensive for each day of life after election of the hospice benefit until death.

The second part of the mandate depends upon the results of the analyses above. Although alternative methods of compensation for high cost hospice care were considered while the analyses were under way, the results of the analyses found no evidence that the current hospice payment policy fails to cover the costs of high cost hospice patients.

Therefore, we recommend continuation of the current Medicare hospice payment system, which includes payment for high cost services within the prospectively determined hospice payment rates, to compensate hospice programs for providing high cost hospice care to Medicare beneficiaries.

I am also sending a copy of this report to the Speaker of the House of Representatives.

Sincerely,

Donna E. Shalala

Enclosure

THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

AUG 17 1994

The Honorable Thomas S. Foley
Speaker of the House of Representatives
Washington, D.C. 20515

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Enclosure

REPORT TO CONGRESS

HIGH COST HOSPICE CARE

Donna E. Shalala
Secretary of Health and Human Services
1993

ACKNOWLEDGEMENTS

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EXECUTIVE SUMMARY

Purpose

Section 6016 of the Omnibus Budget Reconciliation Act of 1989, (OBRA 1989) requires the Secretary of Health and Human Services to:

> "(1) conduct a study of high cost hospice care provided to Medicare beneficiaries under the Medicare program, and evaluate the ability of hospice programs participating in the Medicare program to provide such high cost care to such patients; and
>
> (2) based on such study, develop methods to compensate such programs for providing such high cost care."

In order to implement this charge, an effort was undertaken to clarify the intent of the legislative language, and identify the nature and magnitude of the perceived problem since high cost care can be defined several ways:

(1) the provision of expensive treatments (medications, technologies, surgeries), to patients and/or the provision of services in expensive inpatient settings that result in significantly higher average daily hospice costs for that patient in excess of the Medicare prospectively determined reimbursement rates;

(2) the patient who has the need for a few expensive treatments, which do not result in high average daily hospice costs for that patient;

(3) the patient who exceeds the average hospice length of stay, but does not necessarily exceed average daily hospice costs.

The last two categories of patient are, in fact, not financially problematic. If a patient uses many resources, but the payment system, on the whole, adequately reimburses for those resources, then the hospice has not incurred a reimbursement problem.

In order to understand the nature and magnitude of the perceived problem and to clarify the definition, the Health Care Financing Administration consulted with representatives of the hospice industry, convened a panel of clinical experts, surveyed the clinical literature, and analyzed survey data provided by hospices on patients who used high cost treatments or were otherwise defined by the hospice as high cost. In addition, an analysis was conducted of Medicare beneficiary hospice enrollment and utilization of hospice and other Part A and Part B services. At the start of the study, persons knowledgeable in hospice indicated that most of the expensive patients were those with difficult or uncontrollable pain. Therefore, much of the focus of the

subsequent literature search and the composition of the clinical panel was in the direction of the state of the art in pain management.

The four sources of information used for this study provided useful background discussion of what types of interventions can lead to high costs, but there was little information on exactly what the range of costs might be. The results of the convened panel of hospice and pain control experts provided only anecdotal evidence of cost problem cases. Although the literature review and the clinical advisors identified similar types of interventions, these interventions were infrequently identified as high cost interventions by the hospices responding to the HCIS survey. Most of the "high cost" cases identified in the survey of hospices fall into the latter two categories described above (one time interventions or long stay patients), both of which are not necessarily fiscal problem cases. It appears that the responding hospices identified patients who were high cost because of unusually long lengths of stay rather than those who are receiving atypically costly interventions. In summary, the study found little consensus on what constitutes a high cost case and little reliable information on the cost of these cases or their impact on hospice operating margins.

The second part of the mandate depends upon the results of the first. Thus, methods for compensating hospices for high cost care were to have been developed after it was determined that a problem exists. The basic conclusion from the first part of the study is that there is no convincing evidence that the current hospice payment policy fails to cover the costs of high cost patients. Therefore, methods of compensation for high cost care were not developed. This is based on a number of findings:

(1) Hospice participation in Medicare is growing very rapidly.

Hospice enrollment in 1989 was 33 percent higher than in 1988. The number of hospice facilities serving Medicare patients also increased by 27 percent between 1988 and 1989. It is estimated that 20 percent of all Medicare beneficiaries dying of cancer in 1989 used hospice, up from less than 2 percent in 1984. This growth suggests that the hospice industry is functioning quite well under the current payment methods.

(2) There have been significant increases in Medicare payment rates.

From 1984 (the first full year of the Medicare hospice program) to 1990 there were four increases in hospice payment rates. During this time the average payment for routine hospice care increased by 72 percent. The overall increase in medical prices during these years was 42 percent. In addition, hospice payment rates are currently indexed for inflation. An audit of hospices in 1985 and 1986 found that the operating margins for hospices were 18 percent and

22 percent, respectively. That is, Medicare payments were about 20 percent higher than the costs of treating Medicare patients. Given the increased payment rates, there is no reason to believe that operating margins are not positive.

(3) It was not possible, either from the expert panel or the hospice survey, to clearly define a set of patients or treatments that consistently result in high costs that significantly exceed Medicare hospice payment rates.

The panel identified five groups of interventions which it stated could be high cost, such as intravenous, intraspinal, and subcutaneous medications, and palliative radiation therapy. However, there is little information from the clinical literature regarding the frequency of the need for use of these interventions or their costs. The general panel consensus was that they were infrequent.

The survey of hospices resulted in a large list of interventions used for patients who were identified as high cost by the hospices. Many of the interventions were clearly not high cost of and by themselves (such as the use of morphine). In sum, the definition of high cost patients is vague and interpreted differently among hospice providers. There is no information on the actual cost of these patients or the impact of their care on overall hospice operating margins.

Literature Review

The literature review focused on identifying state of the art pain control technologies and the dimensions of their use. Two types of articles were reviewed: (1) review articles that described general principles of pain control; and (2) clinical research articles describing the use and efficacy of a specific technology on a group of patients in a specific setting. Twenty-four (24) articles were selected for detailed review. The literature findings can be summarized as follows:

- Most cancer patients at the terminal stage experience pain as a major symptom; and pain control for terminally ill patients remains a major challenge despite many recent advances.

- While a multidisciplinary approach to pain control is considered the most effective, the choice of therapies depends on the individual patient, the type of pain the patient is experiencing, and the stage of disease.

- The most common type of therapy for cancer pain is pharmacologic. Typically, treatment begins with nonopioids or nonsteroidal anti-inflammatory drugs for mild pain, moving to "weak" opioids and then to "strong" opioids as pain level

intensifies. The prototypical drugs for this continuum are aspirin, codeine, and morphine.

- There are diverse opinions about which narcotics should be used, appropriate dosage, and most effective route and schedule of administration.

- There are also more invasive procedures (e.g., surgeries) that can provide pain relief, but they are used less frequently.

- The role of total parenteral nutrition in terminally ill cancer patients is controversial, the results of clinical studies showing some degree of harm rather than benefit.

- There is very little cost information for the variety of technologies or treatments discussed. When costs are discussed, typically only purchase costs for a technology are mentioned and there is little information on all the costs associated with a given technology or procedure.

Medicare Hospice Enrollment and Utilization Analysis

An analysis of trends in hospice enrollment and expenditures was conducted using Medicare hospice election information from the Medicare Master Enrollment File and Medicare Part A and Part B payments for those beneficiaries who elected the hospice benefit. The enrollment trends are from 1983 through 1989 whereas the expenditure data are limited to 1987 and 1988 hospice enrollees. The expenditure data include not only hospice expenditures but also Part A and Part B expenditures which occur after hospice enrollment. The major findings are:

- The Medicare hospice benefit grew rapidly in terms of the number of certified hospice providers, the subsequent number of Medicare beneficiaries who elect the benefit, and the resultant increase in Medicare overall hospice expenditures. The number of certified hospice providers has more than tripled from 317 at the end of 1986, the first year of the permanent benefit, to 995 by mid-1991.

- In the 1987 to 1989 period, freestanding and home health based hospices accounted for 42 percent and 38 percent of patients, respectively. However, hospital based hospices are the fastest growing type of provider.

- In 1989, 2 percent of hospices served 18 percent of all Medicare hospice patients. At the other end of the size spectrum, 31 percent of hospices had fewer than 25 Medicare patients in 1989. However, rapid growth in the 1987 to 1989 time period suggests that the smallest hospices are relatively new and will increase patient case load in subsequent years. In addition, size of hospice,

calculated from Medicare enrollment, tends to overestimate financial vulnerability because non-Medicare enrollees expand the reimbursement base.

- The average per diem Part A and Part B expenditures for all 47,000 hospice enrollees under study during 1987-88 was $63.71.

- Total Medicare hospice expenditures increased from $92 million in 1987 to $171 million in 1988. In addition, there were Part A and Part B expenditures for hospice enrollees of $43 million in 1987 and $62 million in 1988. Total Medicare expenditures per hospice enrollee were $4,641 in 1987 and $4,931 in 1988, a 6 percent increase. Payments for hospice services accounted for 68 percent of Medicare expenditures for hospice enrollees in 1987 and 73 percent in 1988.

- The 66,584 enrollees in 1989 represent a 33 percent increase over 1988.

- An estimated 20 percent of Medicare beneficiaries dying of cancer in 1989 used hospice, varying considerably by State.

- Length of hospice stay increased rapidly in the 1987 to 1989 time period. Overall length of stay increased from 38.5 days to 47.9 days, a 24 percent increase. In 1989, the Medicare Catastrophic Coverage Act (MCCA) was in effect and the 210 day limit to the hospice benefit was removed. The 210 day limit was reinstated with the revocation of MCCA (1990); and removed again in 1991.

- There was almost no change in total Medicare expenditures from 1987 to 1988 for persons whose post hospice enrollment life span was less than 90 days. Average Part A hospice expenditures were about $2,000 and additional Part A and Part B expenditures were about $600 in both years.

  These shorter lived persons averaged $85.40 total Part A and Part B expenditures, including hospice, per day from date of election of hospice to date of death in 1987; $83.75 per day of life from hospice election to death in 1988.

- For persons whose life span was greater than 90 days, hospice Part A expenditures increased by about $2,100 per person, but additional Part A and Part B expenditures decreased by about $900 per person, resulting in a net increase in total Medicare expenditures from $12,584 per Medicare hospice enrollee in 1987 to $13,817 in 1988.

These longer lived persons averaged $41.08 total Part A and Part B expenditures, including hospice, per day from date of election of hospice to date of death in 1987; $50.66 per day of life from hospice election to death in 1988.

- Persons who have gaps in their hospice enrollment and/or terminate hospice enrollment before dying are the most expensive in terms of their total Medicare expenditures, because of the length of life. These persons account for 15 percent of all patients, 29 percent of all hospice payments, and 59 percent of all Part A and Part B expenditures among hospice enrollees. However, on a per diem basis, they are the least expensive with $46.54 per diem reimbursement for all Part A and Part B expenditures.

- The Medicare hospice routine home care payment rate in Fiscal Year (FY) 1991 is $79.94, increased from $63.17 during FY 1987-89. The Medicare general hospital inpatient payment rate in FY 1991 is $354.73, increased from $281 during FY 1987-89.

Clinical Advisory Panel Deliberations

Nine experts in pain control and palliative care met for 2 days to discuss the relative prevalence, feasibility of use, and costs of a variety of pain control interventions, as well as other issues related to the provision of pain control interventions in hospices. Early discussion focused on the nature of the high cost problem and, although there were several other concerns identified, the panelists agreed that there were interventions provided to a relatively small number of patients that could present a hospice provider with substantial financial liability. Some suggested that smaller hospices were at higher risk of financial liability and were, consequently, likely to encourage high cost patients to revoke the hospice benefit and return to regular Part A and Part B Medicare coverage, thus "gaming" the system. Although the panelists could not provide cost information, they developed the following list of types of interventions that could lead to high costs:

- intravenous administrations for pain medications, antibiotics, transfusions, hydration, chemotherapy, and total parenteral nutrition;

- medication delivery systems that require intraspinal and continuous subcutaneous access;

- palliative radiation therapy;

- surgeries related to the terminal illness; and

- drugs that cost more than some threshold percentage above the average total cost of drugs normally used in palliation of symptoms for terminally ill patients.

Discussion of this list raised several concerns about providing additional reimbursement for these interventions, including: (1) incentives for inappropriate use or overuse; and (2) appropriate locus of decisionmaking control over choosing to use particular interventions. The discussion also highlighted a list of general considerations, within which the panel felt its recommendations should be considered:

- Short-term reimbursement system modifications should focus on accommodating circumstances under which symptom palliation is provided by a high cost intervention (after less costly alternatives have been found inadequate).

- The patient and hospice provider should have control over making decisions about whether or not particular interventions are medically appropriate.

- Medical guidelines should be in place to provide some check against misuse or abuse of identified interventions. A utilization review mechanism would provide an additional check.

- Evaluation of the impact of modifications to the reimbursement structure should be undertaken.

- More research to further identify interventions or groups of interventions that are costly and how frequently they are used was recommended.

The panelists also suggested potential payment mechanisms and proposed an agenda for further research.

High Cost Interventions Study

The fourth source of information was the High Cost Interventions Study, the analysis of which was done after the meeting of an expert clinical panel. This survey of a sample of Medicare-certified hospices was designed and fielded by the National Hospice Organization to gather basic information on interventions identified as high cost and on the patients receiving these interventions. The survey data were coded and analyzed by the Project HOPE Center for Health Affairs.

While the survey data provide a broad picture of the use of interventions identified by hospices as high cost, there are several caveats to keep in mind when interpreting these data:

- hospice providers self-defined the interventions considered to be high cost;

- cost items were not clearly defined and could not be used; and

- the sample underrepresents hospital and skilled nursing facility based hospices, and overrepresents independent facilities.

The analyses focused on descriptive information about the patients identified as high cost, the interventions these patients received, and how these interventions may be associated with patient outcomes.

- There were 1,681 cases identified as high cost. Over half are Medicare beneficiaries, approximately 25 percent are private health insurance patients, and the remainder are Medicaid, self-pay, and indigent patients (based on source of payment at admission).

- Average length of stay for Medicare beneficiaries was almost twice as high as the average length of stay typically reported overall for Medicare beneficiaries.

- Patients with human immunodeficiency virus (HIV) infection constitute approximately 4 percent of the overall sample, but only about 2 percent of the pool of Medicare hospice patients. Patients with HIV infection are more likely to be covered by Medicaid.

- The distributions of diagnoses across cases and across interventions are similar, thus, it does not appear to be possible to identify high cost cases based on diagnosis alone.

- Information was provided for 3,110 interventions. Interventions were assigned to both a broad category (Type of Intervention) and a more specific category (Specific Intervention). The most frequently reported intervention was use of narcotics, particularly morphine, not a particularly expensive drug of and by itself.

Additional analyses of intervention use across different diagnoses, pain levels, and proportion of total stay accounted for by inpatient days were also conducted. These analyses revealed that:

- Narcotics, chemotherapy, radiation therapy, and supplies were provided more often to patients with cancer diagnoses than to patients with non-cancer diagnoses.

- General medications, enteral nutrition, blood therapy, and antibiotics were used more frequently by patients with noncancer diagnoses. AZT and pentamidine were used more frequently by patients with HIV infection.

- While there are some differences in use of interventions across cases with different proportions of their total hospice stay spent in inpatient care, there are no clear patterns.

Implications for Payment Policy

Presently, Medicare pays for all covered hospice care, including costs associated with high cost individuals and high cost care, through the Medicare hospice prospective payment rate system (based on reasonable costs) and through separate fee-for-service payments for hospice physician services. Because of the prospective features inherent in the Medicare hospice payment rate system, Medicare does not routinely collect data on specific services rendered to specific hospice patients or on specific hospice patient diagnoses through either the Medicare hospice cost reporting or the Medicare hospice billing systems.

Considering the recent increases to the hospice rates (20 percent in FY 1990 and 5.2 percent in FY 1991) and the apparent health of the hospice industry, strong consideration was given to the development and ultimate recommendation of an approach that would have a neutral impact on the budget. If an outlier payment system were adopted, the best approach to achieve budget neutrality appears to be some form of reduction in the current hospice payment rates to fund outlier payments. This would be similar to the approach used to pay for outliers under the Prospective Payment System for hospitals.

It is important to examine high cost hospice care in light of the traditional goals and purposes of the Medicare hospice benefit. The benefit has traditionally been perceived as a means of providing coordinated and personal palliative care, primarily in the home, to the dying patient who has chosen to seek this care as an alternative to the curative care available under the Medicare program generally.

In light of the Congressional request for a study into high cost hospice care, it is necessary that specific high cost treatments or procedures be scrutinized to determine whether they are mainly curative or mainly palliative in nature. We must determine if the care is appropriate for management of the illness or easing pain, rather than combating the illness or prolonging the patient's life. There has always been a segment of the hospice industry who favor palliative care in addition to curative care rather than as a substitute for curative care. We must continue to keep traditional hospice goals in mind to ensure that any outlier system that is considered continues the traditional and statutory focus of hospice on palliative care.

In the first phase of the national hospice survey, respondent hospices identified over 10 percent of their total case load as high cost. From a payment policy perspective, such a surprisingly high figure raises questions as to whether these cases represent true "outliers". It appears as though hospices have identified long-stay patients rather than true (per diem) cost outliers. Since Medicare payment is on a per diem basis, Medicare is already paying hospices higher overall amounts for cases hospices identify as high cost. The analyses of the longest lived Medicare hospice patients show that the group that disenrolls from hospice before death (12.9 percent) has about average daily hospice costs while in hospice ($78.66 compared with the average of $80.19), but lower total Medicare expenditures per day of life ($45.01) than the average hospice patient ($63.71).

Several approaches were initially considered in the examination of alternatives to develop methods to compensate hospice programs for high cost hospice care, including:

(1) Establishment of a dollar threshold amount per beneficiary, when exceeded, would trigger outlier payment.

The lack of charge data on particular services furnished to individual hospice patients makes outlier payment approaches based on individual patient dollar amounts problematic in terms of accountability and potential for payment system abuse.

(2) Identification of specifically identifiable therapies to trigger outlier payment. Linking outlier payment to the existence of a particular therapy is problematic in that there is little information known on the total costs associated with a given technology or procedure. Even if acceptable cost information was available, pricing of specific interventions or categories of interventions would have been very difficult and cumbersome. Linking outlier payments to a particular therapy may also present difficulties from a program integrity view.

(3) Identification of specific conditions or patient diagnosis, which would trigger outlier payment. Linking outlier payment to the existence of a particular diagnosis was not feasible. Although the current hospice billing system could most likely be modified to include coding for patient diagnosis, what hospices identified as high cost cases do not appear to be related to individual patient diagnosis.

(4) Continuation of the current Medicare hospice payment system, which includes payment for high cost services within the prospectively determined hospice payment rates. Continuation of the current Medicare hospice payment system, which includes payment for high cost services within the prospectively

determined hospice payment rates, seems the most feasible administratively, and seems to provide the most protection against payment system abuse. The budget impact of the continuation of the present system would, of course, be neutral, and individual hospices concerned with the financial impact of an occasional high cost patient could explore the availability of reinsurance through the private sector.

With regard to the Clinical Panel's broad categories of high cost procedures, we believe more consideration needs to be given as to how interventions within these categories are paid under the current payment system. While each item mentioned by the panel undoubtedly can be costly, we believe the financial risks associated with the occasional provision of these services, where appropriate, can be managed within the present hospice payment system.

The data collected through this research effort seem to argue against the need for any modification to the current prospective payment system to provide separate payment for high cost "outlier" cases. Much of the anecdotal information which asserts that Medicare payment is inadequate for hospice care appears contradicted by the strong growth experienced by the benefit in recent years. The Medicare hospice claims data show low per diem Medicare Part A and Part B reimbursements for that group of patients who disenroll from hospice prior to death. This is the group that some hospice administrators have indicated must "game the Medicare system" in order to obtain more costly, but appropriate, treatments. The average per diem expenditures for this group could be covered under the existing hospice daily rates.

When one considers this information, it appears that the benefits to be gained by altering the hospice benefit to allow for increased payment to hospices for services that are already covered in the per diem rates or in other areas of the Medicare program may not justify the resulting complications and disturbance to a coverage and payment system that is otherwise considered to be simple and effective.

Conclusion

In summary, there does not appear to be consensus on the clinical appropriateness of some of the high cost procedures and technologies for hospice patients that were investigated in the course of this project. The clinical literature indicates that some of the more expensive technologies identified at the start of the study, specifically total parenteral nutrition or intravenous administration of narcotics, may either not be clinically appropriate or may be last steps in the clinical strategy of treatment after the use of less expensive or invasive treatments. The importance of clinical decisionmaking for individual patient situations is clear and was emphasized by the clinical advisory panel. It is not clear that it is possible, or desirable, to identify high cost procedures as the basis of any hospice reimbursement adjustments.

The analyses of the clinical literature, the survey information on the hospice identified high cost patient, and the advice of experts do not present a clear picture of a problem. Rather, extremely high cost (per day) patients appear to be infrequent; inconsistency exists in the terminology and perception of what constitutes a high cost hospice patient; and there is infrequent use of the few expensive surgical procedures for which there was consensus by the clinical advisory panel. From the available sources, there is no strong evidence of there being many hospice patients whose necessary care results in daily expenses significantly in excess of the Medicare payment rates, and no evidence that there is a problem of sufficient magnitude to justify a modification of the existing payment mechanism.

Recommendation

We recommend continuation of the current Medicare hospice payment system, which includes payment for high cost services within the prospectively determined hospice payment rates, to compensate hospice programs for providing high cost hospice care to Medicare beneficiaries.

CHAPTER 1

BACKGROUND AND STUDY APPROACH

1.1 Purpose

Under section 6016 of the Omnibus Budget Reconciliation Act of 1989 (OBRA 1989), the Secretary of the Department of Health and Human Services is required to submit to Congress a report identifying methods to compensate hospices for providing high cost care to Medicare beneficiaries. Specifically, the charge to the Secretary is to:

> "(1) conduct a study of high cost hospice care provided to Medicare beneficiaries under the Medicare program, and evaluate the ability of hospice programs participating in the Medicare program to provide such high cost care to such patients; and
>
> (2) based on such study, develop methods to compensate such programs for providing such high cost care."

The purpose of this study is to provide background information on high cost hospice care that will contribute to the Secretary's report to Congress. Using information from three sources, this study set out to: 1) identify which Medicare hospice services are high cost; 2) determine or estimate the average cost of these services; 3) ascertain the dimensions of use of high cost services; and 4) identify the characteristics of patients receiving high cost hospice care. Dimensions of use include measures such as number of patients receiving these services, frequency and duration of use of these services, the diagnoses involved, and trends in the use of these procedures for palliative versus curative care.

1.2 Background

Growth of the Hospice Industry

Since the early 1970s, hospice care in the United States has evolved from being a philosophy of care for dying patients and their families to a recognized form of health care provision (McCann, 1988). Hospices provide symptom management, pain control, and counseling for the terminally ill. The objectives of hospice care are to maximize patient autonomy during the last weeks of life and to allow terminally ill patients to die at home, among family, with as much dignity as possible and relatively free of pain. The traditional emphasis is on low-tech, noninvasive care that provides palliative rather than curative treatment. Generally, palliative care focuses on pain management and

symptom control whereas curative care focuses on eliminating the condition and curing the patient.

Increasing acceptance of hospice care as an integral part of the health care system has been fueled in part by the coverage of hospice care benefits in private health insurance policies and the establishment of hospice benefits by both Medicare and Medicaid. The rapid growth of the industry over the last two decades indicates the appeal of this "low-tech, high-touch" alternative to the typically more invasive "high-tech" nature of care for the terminally ill in conventional, acute care hospital settings (Beresford, 1990a; 1990b). Between 1980 and 1986, the number of hospices in the United States grew from approximately 269 to over 1,500 (Tames, 1987). In 1983, according to estimates from the National Hospice Organization (NHO), hospices cared for 100,000 terminally ill patients (Tames, 1987). This has approximately doubled in 6 years, to an estimated 200,000 in 1989. Since most hospice patients are elderly (over 60 percent of patients are over 65), most are Medicare-eligible (Beresford, 1990a).

Hospice Benefits Under Medicare

Under the Tax Equity and Fiscal Responsibility Act of 1982, Medicare was authorized to provide hospice care benefits. The Medicare hospice benefit went into effect on November 1, 1983, and was designed to provide an alternative type of care for terminally ill Medicare beneficiaries. All Medicare Part A beneficiaries are eligible to elect the hospice care benefit, and care provided by facilities certified as hospices by Medicare must meet certain standards and conditions of Medicare program participation.

Under Medicare, hospices are paid one of four predetermined daily rates for each day a patient is enrolled under the Medicare hospice election. The payment varies according to the level of care provided to a patient on a particular day. Hospices bill Medicare for the number of days of each type of care provided to their patients.

These payment rates, prospectively set, include: routine home care ($79.94 per diem in FY 1991); continuous home care (up to $465.40 per diem for 24 hours of care in FY 1991); inpatient respite care ($82.48 per diem in FY 1991); and general inpatient care ($354.73 per diem in FY 1991). These rates are intended to cover every service provided under the Medicare hospice benefit except hospice physician services, which were paid separately to the hospice on a reasonable charge basis. However, since January 1992, all physician payments have been made based on the Medicare fee schedule.

In addition, there are caps on annual aggregate per patient expenses and inpatient hospital utilization. For the most recent cap year ending October of 1990, the average

annual per patient expense is capped at $9,787. This cap is applied on an aggregate basis (e.g., for 10 patients, the total reimbursement for their care is compared to 10 x $9,787). Thus, while one patient could require care costing greater than $9,787, other patients at the hospice for whom costs are not as high could offset this cost and the aggregate cap would not be reached. Currently, according to the Health Care Financing Administration (HCFA), no hospices have reached this cap.

The legislation intended to emphasize home care rather than institutionalized forms of care. Thus, Congress placed a limit on aggregate use of inpatient care. No more than 20 percent of total days spent under the Medicare hospice benefit can be for inpatient care. There is a reimbursement formula used to pay hospices for inpatient days in excess of this limit, which effectively reduces reimbursement for the excess days to the routine home care level.

There are two circumstances under which a Medicare hospice benefit patient can receive Medicare payment for services provided outside the scope of Medicare hospice benefits: 1) when the patient requires treatment for a condition unrelated to the terminal illness; and 2) when services are provided by the patient's attending physician. Costs for these types of services, which are not considered hospice care, are not counted in applying the aggregate cap.

The hospice benefit under Medicare has experienced rapid growth over the last 5 years. Medicare hospice benefit expenditure data show that, in FY 1985, Medicare paid approximately $10.3 million for hospice services (HCFA, Bureau of Data Management and Strategy, 1987). Recent data indicate that Medicare benefit payments for hospice care increased to $129 million in 1988 and by another 68 percent to $216 million in 1989 (HCFA, 1990). Most of this growth is accounted for by increases in the number of beneficiaries electing the hospice benefit. Between 1984 and 1986, the number of beneficiaries who elected the hospice benefit increased from 2,000 to 11,000 (HCFA, Bureau of Data Management and Strategy, 1987). The number of beneficiaries increased to 44,000 in 1988 and by 41 percent to 62,000 by 1989.

All Medicare Part A beneficiaries are eligible for hospice care if their physician can certify that the beneficiary is terminally ill (a life expectancy of 6 months or less), and that the beneficiary has elected to receive hospice services. While covered as a hospice beneficiary, the patient retains Medicare Part B eligibility for attending physician services and Part A and Part B coverage for services not related to the terminal condition. Medicare reimbursement for services related to the terminal illness and not provided by or arranged through the designated hospice is waived. A beneficiary can revoke the hospice election at any time by signing a revocation statement.

In 1985, the majority of patients were over 65 years old, had an average length of stay of 32.1 days, and were most likely to have a diagnosis of cancer (93.7 percent). Between 1988 and 1989, average length of stay has increased from 37.2 days to 46.4 days (25 percent). Over the same time period, average reimbursement per patient increased from $2,919 to $3,472, a 19 percent increase. Routine home care accounts for over 90 percent of billed days (86 percent of Medicare reimbursements).

Since the Medicare hospice benefit was enacted in 1982, the hospice industry has experienced continuous Congressional support. A sunset provision in the initial legislation was repealed by the Consolidated Omnibus Budget Reconciliation Act of 1985, thus the hospice benefit became a permanent benefit under Medicare Part A. The per diem rates have also been periodically increased, primarily in response to industry concerns that the initial payment rates (developed on experience with an early demonstration project) were too low or at least have not kept pace with inflation.

A study conducted for HCFA by Jack Martin and Co. (1988) examining the cost data in non-Medicare-certified hospices showed that most hospices were within the limits of the Medicare per patient costs and inpatient day limits. In addition, a study evaluating the Medicare hospice benefit conducted by Abt Associates showed that in FY 1985, Medicare total margins averaged 18 percent, and averaged 22 percent in FY 1986. Of the hospice providers in the study sample, 86 percent earned positive net revenues from the Medicare program (Abt Associates, 1989). Thus, at least during this time period, the Medicare payment rates appeared to adequately cover the costs of providing hospice care to Medicare beneficiaries.

New Challenges Facing the Hospice Industry

Despite industry success in gaining acceptance by both public and private payers, hospices are facing new challenges as the concept of hospice care shifts from being a volunteer-intensive social movement to becoming an integral part of the health care system. The industry now faces increasing competition, complex third party reimbursement processes and requirements, and increasingly difficult decisions about what services should be provided and which patients should be admitted.

A clear definition of what a hospice is or what combination of services a hospice should provide does not exist. There are a variety of organizational structures and ownership arrangements--freestanding, hospital-affiliated, community-based, and home care agency services--and a range of medical and support services that can be provided to terminally ill patients and their families (Davis, 1988). As the industry continues to grow and change, a number of new arrangements are emerging. Congregate housing arrangements are being developed to provide access to care for potential hospice patients who lack a primary caregiver. Other developments include collaboration with nursing homes to provide services in a facility setting rather than at the patient's home,

and adult day care arrangements for patients who are too sick to stay at home while their primary caregiver is at work. All of these arrangements can be fit within the existing reimbursement structure.

In addition, the traditional low tech, noninvasive approach to providing care is being challenged by rapid developments in pain control technology. Medical and technological advances continue to make high tech treatments available in nonhospital settings, even in the home. The definition of high cost technology is arbitrary, but high technology interventions frequently have complex mechanical features and they tend to be expensive. As these advances continue to develop, however, several financial as well as ethical concerns become more visible.

For example, continuous drip intravenous morphine can offer much greater control of intractable pain, but frequently, intermediate, less invasive steps to control the pain are ignored. In addition, the family is faced with using a new high-tech intervention which is complicated to operate (Beresford, 1990b). A variety of sophisticated pumps for delivering narcotic drugs, even some which the patient can control the amount of medication he or she receives, are available to the patient. These pumps offer different advantages and may change the nature of the physician/nurse relationship with the patient. Total Parenteral Nutrition (TPN) is another example of a technology with financial and ethical complexities as it may prolong a dying patient's life without necessarily increasing the patient's comfort.

Acquired Immune Deficiency Syndrome (AIDS) patients also are challenging the ability of hospices to provide care for the chronically ill. While the philosophy of hospice care seems ideally suited to care for AIDS patients, these patients often require costly care and thus can put hospices in difficult financial situations. Life-extending treatment, such as AZT, is forcing hospices to change their attitude toward these types of treatments that may not be curative but do prolong life. Although challenging the hospice industry as a whole, the still infrequent incidence of AIDS in the Medicare eligible population does not constitute a major problem under the Medicare hospice benefit, the focus of the Congressional report request.

It should be noted, however, that interventions considered high cost are not necessarily always high tech. In addition, not all hospices agree that the provision of state-of-the-art pain control is a necessary step for providing hospice care. Lack of consensus within the industry about who are appropriate patients and what is appropriate care indicates the difficulty facing policy development.

As the definition of hospice care evolves, and the range of treatments that can be provided in a hospice-based home care program become more sophisticated, the costs associated with providing some of these treatments apparently are prohibitive, according to many hospices. Some hospices are concerned that Medicare reimbursement levels

are too low to permit the use of these more expensive technologies, and thus restrict access to important developments in palliative treatments. Other hospices assert that current Medicare reimbursement rates allow them to at least "break even" on Medicare patient care. Evidence to date shows that, on average, the Medicare prospective per diem rates are adequate for covering the full costs of care for Medicare hospice benefit patients. However, for a small number of terminally ill patients using the more expensive and perhaps more effective techniques for controlling pain, the costs associated with these techniques may lead to substantial financial liability.

Little is known, however, about the patterns of use and expenditures for these new high tech and/or high cost interventions. In order for HCFA to better understand the costs of providing services involving these technologies and the patterns of use across different sites of care, background information on the costs and dimensions of use will be needed. This study provides an exploratory look at what information is currently available on the use and costs of these technologies.

1.3 Overview of Approach

The research approach for completing this study consisted of four major tasks:

1) Conducting a literature review of medical and technology journals to identify state-of-the-art care and pain control technologies that are used in hospice and other settings for terminally ill patients;

2) Assembling a Clinical Advisory Panel (CAP) of experts in the use and provision of state-of-the-art palliative care technologies across a variety of settings, conducting the CAP meeting, and summarizing the panel deliberations;

3) Analyzing Medicare hospice benefit utilization and expenditure patterns; and

4) Analyzing NHO survey data from Medicare-certified hospices to identify patterns and frequency of use for technologies identified as being high cost.

The findings from these tasks are presented in this report. The remainder of this report is organized as follows. Chapter 2 presents the findings from the literature review, Chapter 3 summarizes Medicare hospice enrollment and reimbursement experience, Chapter 4 summarizes the CAP meeting deliberations. Chapter 5 discusses the findings of the survey data analysis and Chapter 6 presents the implications for reimbursement policy. Finally, Chapter 7 synthesizes the findings from each of the major tasks. An annotated bibliography, summary transcript of the CAP meeting, and a copy of the NHO survey appear as the appendices.

CHAPTER 2

LITERATURE REVIEW

2.1 Purpose

The purpose of the literature review was to identify state-of-the-art care and pain control interventions that are used in hospice and other settings for terminally ill patients. This review had two goals: 1) to gather available information on costs and use of interventions provided in hospice care that could supplement data collected from other sources in this study; and 2) to strengthen research team knowledge of state-of-the-art technologies and facilitate their interaction with CAP. Specifically, the literature review sought to provide background information to answer the following types of questions:

- What technologies are effective in controlling pain?
- Does the effectiveness of these technologies differ for different diagnoses or disease stages?
- To what extent are these technologies being used in hospice and nonhospice settings?
- How is use of these technologies changing?
- What effective techniques are not being used optimally in hospice settings and why?
- How is use of these technologies changing the role of both formal (hospice) and informal (family) caregivers?
- What are the costs associated with use of these technologies?

Medical, trade, health policy, industry, technology, and health care marketing literatures were reviewed. Using primarily four of the literature data bases maintained by the National Library of Medicine, over 900 articles on pain control technologies initially were identified. These data bases were: 1) MEDLINE, which abstracts articles from over 3,500 major medical journals; 2) CANCERLIT, a data base of cancer literature; 3) AIDSLINE, a data base of AIDS literature; and 4) HEALTH, a data base containing references to health planning and management information. In addition, articles or publications provided by members of the CAP were reviewed.

There were generally two types of articles identified: 1) review articles that described general principles of pain control; and 2) clinical research articles that described the use and efficacy of a particular technology on a group of patients in a specific setting. Most of these articles did not mention the costs associated with the technology or intervention, and those that did typically noted the purchase cost but not other types of costs (e.g., the costs related to surgery, patient monitoring or necessary nursing visits, etc.). In addition, the setting in which the technology or intervention was used was not always identified. While some articles alluded to postoperative or hospice care, the issue was not explicitly addressed.

Twenty-four articles were selected for detailed review. These articles were chosen to provide enough background information to facilitate discussion with the CAP and to develop an understanding of the set of issues relevant to pain control in the hospice setting. Given the necessarily limited number of articles reviewed, it was possible to describe in broad terms the types of interventions that are being used to treat terminally ill cancer patients, but it was not possible to provide detailed answers to each of the questions listed above. An overview of the selected literature is provided here, and an annotated bibliography appears as Appendix B.

This section summarizes the information from these 24 articles. The literature provided background information in four general areas: 1) prevalence and definition of cancer pain; 2) approaches to pain control; 3) nutritional support and hydration; and 4) cost information.

2.2 Prevalence and Definition of Cancer Pain

A major goal of hospice care is controlling cancer-related pain. While the hospice movement has had perhaps its largest influence in treating physical pain, hospice care is intended to palliate "total pain," including physical, mental, social, and spiritual pain (Rhymes, 1990). Many of the interventions discussed in this chapter are targeted to controlling the physical pain frequently experienced by terminally ill cancer patients.

The World Health Organization estimates that over 3.5 million people suffer from cancer pain daily (Haskell (ed.), 1989). Estimates of the prevalence of cancer pain range from 20 percent to 95 percent of all cancer patients, depending on the type of cancer and the stage of disease (Portenoy, 1990; Kinzbrunner et al., 1990; Haskell (ed.), 1989). Typically, patients in early disease stages experience less pain than patients in later stages of disease. Most cancer patients at the terminal stage (71 percent according to one study) experience pain as a major symptom (Haskell (ed.), 1989).

Cancer pain refers to a heterogeneous set of syndromes and can have multiple origins (Foley, 1985; Haskell (ed.), 1989). In addition, the level and intensity of pain in a given patient is difficult to determine because the pain response is highly subjective. With

cancer patients, pain can be either acute (pain leading to a diagnosis of cancer or pain associated with the particular cancer therapy chosen) or chronic (associated with progression of the disease or with related therapy). However, the pathophysiologic mechanisms leading to these different pain experiences are not well understood. In light of the wide range of physiologic symptoms and diverse responses to various types of pain control, the need for individual patient assessment is clear (Foley, 1985).

2.3 Approaches to Pain Control

Pain control for terminally ill patients remains a major challenge, despite many recent advances. Although pain level is difficult to measure, pain is frequently inadequately controlled as the disease progresses to advanced stages (Denobile, 1990; Kinzbrunner et al., 1990). Foley (1985) suggests that the most effective treatment for cancer pain is a multidisciplinary approach including analgesic drug therapy, neurosurgical and anesthetic procedures, behavioral methods, and supportive care. The combination of therapies chosen, however, depends on the patient, the type of pain the patient is experiencing, and the stage of disease.

For cancer pain, the most common type of therapy is pharmacologic management. Appropriate use of drugs can provide substantial pain relief in a majority of patients suffering from cancer pain. Drugs used for cancer pain can be categorized into three classes: 1) nonopioids and nonsteroidal anti-inflammatory drugs (NSAIDs); 2) opioids (narcotics); and 3) adjuvant analgesics (Portenoy, 1990). A widely accepted guideline for choosing which class of drugs to use is the World Health Organization's "analgesic stepladder." Patients with mild pain should be treated with an NSAID or other nonopioid, perhaps in conjunction with an adjuvant analgesic. If NSAIDs are ineffective in controlling patient pain, a "weak" opioid is the next choice, and a "strong" opioid should be used for severe pain. The prototypical drugs for this continuum are aspirin, codeine, and morphine. Clinical trials indicate that about 70 percent of patients find pain relief with the optimal use of these three drugs (Portenoy, 1990). In the hospice setting, nonopioid-opioid combinations are frequently used (Wener, 1988).

There are several controversies associated with the use of narcotic analgesics: 1) choice of analgesic; 2) route and schedule of administration (transdermal, oral sublingual, epidural and/or intrathecal); and 3) risks of psychological dependence with long-term use (Foley, 1985). Each of these areas has its own set of clinical debates. For example, opioid analgesics (narcotics) are the mainstay pain therapy for most cancer patients. While all of these drugs have similar efficacy, they vary in potency. Morphine is typically used as it is widely available and its clinical use is widespread. In at least 90 percent of patients, intractable pain can be adequately controlled with morphine (Wener, 1988). Combinations of drugs can improve pain relief without increasing the narcotic dose, however, there appears to be little consensus on what are the appropriate combinations of medications and their dosage levels. In addition,

adjuvant analgesics (a diverse group of drugs with other primary indications that may provide additive analgesia) can be used, but there is little scientific evidence of their benefit or superiority to other methods (Foley, 1985; Enck, 1989(a)).

There are also diverse opinions about appropriate routes and schedules of administration. Oral administration is considered to be the safest, most economical approach if a patient can swallow and absorb the drug. There are a wide variety of other routes of administration. Administration of medications by intravenous (IV) and subcutaneous infusion is often used, but these routes may sometimes be a weaker form of pain control than more targeted, nonsystemic routes of administration. Patients with gastrointestinal, oral, and esophageal cancer typically cannot be given pain medications orally and are instead given medications intravenously.

When pain is poorly controlled with systemic (oral or parenteral) narcotic administration, or the patient experiences limiting side effects, intraspinal delivery may provide improved pain relief. Over the past decade, cancer pain control through epidural infusions of narcotics have also become increasingly popular (Denobile, 1990). These methods, involving administration of small doses of narcotics directly to central nervous system locations, can be viewed as one "extreme of the spectrum of interventional analgesic treatment" (Patt, 1989). These measures have several advantages over systemic delivery: 1) selective and longer-lasting analgesia; 2) achievement of higher levels of pain control with smaller dosages; and 3) reduced patient experience of opioid-mediated side effects (Lubenow, 1990; Patt, 1989). In postoperative patients, several studies indicate that one dose of morphine administered spinally has a longer effect than a similar IV dose. In addition, the hourly dose of morphine has been suggested to be five times higher when given intravenously as compared to when given through the extradural route (Gustafson, 1988). Patient quality of life also appears to be significantly improved (Drexel, 1989).

This type of administration, however, requires skilled personnel and is technically more difficult. For example, a fully implanted pump and subarachnoid catheter insertion usually requires a neurosurgeon, and an epidural catheter insertion requires an anesthesiologist (Lubenow, 1990). The increased side effects (e.g., infections, catheter dislodgement) associated with these interventions, however, promote the need for more frequent nursing supervision. Therefore, the insertion and monitoring costs associated with these newer rates of delivery can be significant.

Another type of intervention, patient-controlled analgesia (PCA) is a recently developed drug delivery system that allows patients to self-administer predetermined doses of opiate analgesics. This system is for patients in severe pain. One study (Swanson, 1989) concluded that cancer patients with severe pain who require parenteral narcotic administration and typically need inpatient care, could be treated successfully at home using PCA. This drug delivery system is much more complex than the typical

intravenous pump, however, and may at least initially require more nursing visits to educate patient and family about its use.

Future developments in drug delivery systems are expected to include transdermal administration of narcotics. Although transdermal systems are not new (nitroglycerin and scopolamine are current examples of use), to date a transdermal system for narcotic administration has not been approved by the Food and Drug Administration. Several trials involving fentanyl citrate, a synthetic narcotic that may be as much as 75 times more potent than morphine, appear to show that it is safe and effective in a postoperative setting. As a noninvasive technology, transdermal systems are an appealing technology for the hospice setting because, like oral medication, they are easily administered.

Surgical procedures also can be used to treat cancer pain, particularly if pharmacologic management is unsuccessful. According to Long (1980), destructive procedures should not be used in the early phases of cancer pain and the risks of the interventional procedure may be too great for many patients. To undertake these procedures: 1) the cause of pain should be clearly understood; 2) the pain should be serious enough to warrant drastic treatment; 3) the procedure used should be the most appropriate for the pain and for the expected longevity of the patient; and 4) the patient's life span should be long enough to warrant the procedure (Long, 1980). For example, diagnostic and therapeutic nerve blocks (anesthetic management of cancer pain involving the insertion of a needle close to a peripheral nerve, neural plexus, or nerve root to inject a solution that will give a temporary or prolonged neural blockade) can lead to pain relief for up to 6 months. The precise type of nerve block performed depends on the source of pain and type of cancer affecting the patient (Ferrer-Brechner, 1985).

2.4 Nutritional Support and Hydration

Types of care other than pain control are also controversial. Two articles provided background information on nutritional support, including TPN. Malnutrition is reportedly a common symptom among terminal patients. One study stated that 80 percent of terminal patients experience malnutrition (Miller and Albright, 1989). A position paper from the American College of Physicians assessed the pooled results of 12 randomized controlled trials of parenteral nutrition and concluded that "the evidence suggests that parenteral nutritional support was associated with net harm, and no conditions could be defined in which such treatment appeared to be of benefit" (American College of Physicians, 1989).

While there is a lack of information on the determinants of malnutrition in cancer patients, studies of artificial nutrition show little benefit. However, providing food and sustenance to a patient often symbolically expresses family care and compassion. Thus, emotional considerations may hinder family understanding that nutritional support may

not be helpful, and may even worsen the patient's quality of life (Miller and Albright, 1989).

2.5 Cost Information

Very little cost information was reported in the selected literature. One article on pain control in the hospice setting reported some information on the product costs for several drugs. Wener (1988) listed manufacturer prices for examples of nonopioids, opioid-nonopioid combinations, and morphine. Costs for nonopioid analgesics range from $2.55 for 12 300-milligram suppositories of acetylsalicylic acid (aspirin) to $12.71 for 50 600-milligram tablets of ibuprofen (motrin). For nonopioid-opioid combination products, prices range between $10.20 for 100 Roxicet tablets to $68.41 for 100 Tylenol with codeine elixir preparations. Costs for morphine depend on the delivery system and/or route of administration: costs (from one company) range from $5.96 for 100 milliliters oral solution of morphine sulfate to $71.25 for 250 30-milligram morphine sulfate tablets.

According to Wener (1988), "as needed" dosing is not the preferred regimen, and the standard dosing interval is every 4 hours. The usual oral morphine starting dose is 5 to 10 milligrams, and the usual maintenance dose is less than 20 milligrams. If these dosages are ineffective, incrementally higher dosage levels are pursued. Dosage information for other forms of delivery, such as controlled-release, soluble, or suppositories, was not provided in the article (Wener, 1988). In addition, there is a lack of information about the cost of intravenous drug delivery.

Somewhat more information was available on pump delivery systems. Although complete internalization of a drug delivery system (e.g., implantable pumps) is advantageous, it is costly (Denobile, 1990). While the costs of a course of chronic intraspinal opioid therapy are difficult to estimate, costs for implanting epidural systems cited in the reviewed articles range between $1,000-$2,000 and between $6,000-$10,000 for implanting internalized pumps (Patt, 1989). Again, knowledge of dosage level and frequency of dose is important. According to Patt, continuous infusion epidural administrations of 5-20 milligram daily doses of morphine commonly achieve total pain relief. Subarachnoid pump systems typically involve filling a 50 milliliter reservoir every 14-21 days. Another recent study protocol examining pain relief through intrathecal infusion (using an implantable pump) for 53 patients showed that the median infusion dose at 2 weeks was 3.8 milligrams per day. In addition, although there was significant variation in dose incrementation, the mean spinal morphine dose at 16 weeks had increased about two and a half times (Onofrio and Yaksh, 1990).

One article (Kwan, 1989) basically catalogued high technology intravenous infusion devices. While stating that approximately "40 percent of all drugs and fluids administered in the hospital setting currently are administered intravenously," there is

little mention of the extent to which these types of devices are used in the hospice setting. The article provides comprehensive details about some of the newer infusion devices and classifies them in a variety of ways. Pumps can be classified by type of programming capabilities (multiple rate or multiple solution, PCA), application (syringe style, bottle), or setting in which they can be used (for hospital or ambulatory care use). For the variety of pumps reviewed in this article, purchase costs ranged from $1,860 to $5,850. These costs, however, do not include the associated costs of implantation, monitoring, or maintenance.

CHAPTER 3

MEDICARE HOSPICE ENROLLMENT AND REIMBURSEMENT ANALYSIS

3.1 Medicare Hospice Population Characteristics

The growth in Medicare hospice enrollment since the beginning of the program is shown in Table 3-1. The Medicare hospice benefit, which was conditioned with a 3 year "sunset" provision, was implemented in October 1983. During the last 2 months of 1983, only 135 persons elected the benefit. In 1984, the first full year of the program, there were just under 5,000 hospice enrollees. Two years later, in 1986, enrollment had quadrupled to over 21,000.

Since Congress made the benefit permanent in late 1986, there has been substantial sustained growth in beneficiary elections, tripling to over 66,500 beneficiaries enrolled in 1989. The increase from 1988 to 1989 was 33 percent, indicating continued rapid growth in the most recent time period.

The demographic composition of the population has remained essentially unchanged over the 6 year period, except for a slight rise in age. The percentage of persons aged 85 and over has increased from 10 percent in 1984 to 14 percent in 1989. The average age has increased by about 1 year, from 73.7 years in 1984 to 74.9 years in 1989. In all years, males comprised slightly more than one-half of enrollees. White persons accounted for about 90 percent of enrollees in all years. The vast majority (95 percent) of enrollees are Medicare eligible due to old age.

Most of the remaining enrollees are Medicare eligible due to disability although a few persons have entitlement due to end-stage renal disease (ESRD). In 1989, there were 128 hospice enrollees whose entitlement was due to ESRD. However, many elderly and disabled persons have ESRD even though that is not their reason for entitlement. Persons with ESRD accounted for about 1 percent of all hospice enrollees in most years, over 400 such patients in 1989.

At the same time that Medicare hospice enrollment has been increasing, deaths due to cancer among the aged have also been increasing, although at a much lower rate. In 1984, there were about 291,000 cancer deaths among persons ages 65 and over. By 1988, the number of deaths had increased to 324,000, an annual rate of increase of 2.7 percent. Consequently, the penetration of hospice use among dying cancer patients

has rapidly increased. This is shown in Figure 3-1.[1] In the first full year of the Medicare hospice program (1984), less than 2 percent of Medicare beneficiaries dying of cancer used hospice. This percentage increased rapidly in succeeding years up to 20 percent in 1989, and will most likely exceed 23 percent in 1990.[2]

It appears clear that, at least through the end of 1990, the hospice program grew rapidly. The potential level of persons is hard to estimate. There are a number of factors which will tend to limit hospice enrollment among all cancer patients. First, there is patient and physician preference. There is no reason to believe that all cancer patients and their physicians will prefer hospice care to more conventional care. Second, Medicare's hospice benefit is largely a home care benefit and is dependent, in part, on a family support system at home. Not all patients have this support. Third, not all cancer deaths proceed in a similar manner. Certain cancers, such as leukemia, are more amenable to medical interventions and will probably not attain the same hospice use levels that are seen in lung, breast, and colon cancers. Finally, enrollment will also be limited to some extent by the availability, and Medicare participation, of hospice providers.

As shown above, by 1989, Medicare hospice enrollment had reached the point where a significant percent of persons dying of cancer were using the benefit. Table 3-2 shows estimated hospice penetration rates by State for 1989. Penetration is here defined as the percent of cancer deaths in which hospice was used. The estimates of cancer deaths were taken from the National Center for Health Statistics (NCHS).[3]

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[1] The percents in Figure 1 are rough estimates of hospice penetration for a couple of reasons. First, because not all persons over age 65 are entitled to Medicare, the number of cancer deaths from NCHS overestimates the potential Medicare population dying of cancer. On the other hand, because not everyone using a hospice is dying of cancer, total hospice enrollment overestimates the cancer portion of hospice. These two effects probably offset each other to some extent.

[2] Estimates of cancer deaths for 1989 and 1990 were made by inflating the 1988 NCHS counts by 2.7 percent each year. Medicare hospice enrollment for 1990 was estimated (approx. 80,000) by extrapolating the rate of enrollment through October for the remaining 2 months.

[3] Advance Report of Final Mortality Statistics, 1988 Monthly Vital Statistics Report, Vol. 39, No. 7, Supplement, November 28, 1990.

Overall, it is estimated that about 20 percent of persons who died of cancer in the Medicare population elected the hospice benefit in 1989. This varied considerably by State. Eight States had penetration rates of 33 percent or greater including such large States as Florida (38 percent) and Texas (33 percent). Colorado had the highest rate at 61 percent. On the other hand, 10 States had penetration rates of less than 10 percent, although they tended to be States with larger rural populations such as Oklahoma, Nebraska, and South Dakota.

Table 3-2 also shows a comparison of hospice certification with hospice counts from the NHO guide to hospices. As of 1989, slightly less than one-half (47 percent) of all hospices were Medicare certified. Like Medicare hospice enrollment, certification varies by State, but the two are not necessarily related. In some States, notably Florida and Colorado, hospice enrollment is high and most of the hospices are certified. However, New York has a high rate of certification (93 percent) but a relatively modest penetration of hospice use among cancer deaths (14 percent).

Patient Distribution by Hospice Type

Hospice enrollment for the years 1987 to 1989 by type of hospice is shown in Table 3-3. The most common types of hospice in terms of enrollment are freestanding and home health based hospices which accounted for 42 percent and 38 percent of hospice enrollment during these years, respectively. Hospital based hospices accounted for 16 percent of patients and Skilled Nursing Facility (SNF) based hospices accounted for only 3 percent of patients. However, market share has changed somewhat during these 3 years. Overall, there was a 40 percent annual increase in hospice patient enrollment between 1987 and 1989. However, hospital based hospice enrollment increased by 63 percent per year. Hospital based facilities accounted for 14 percent of all patients in 1987 and 19 percent of all patients in 1989.

There were few meaningful differences in demographic characteristics across hospices. All hospice types had 6 percent of patients under age 65 and about 13 percent over age 85. About one-half of patients in each type of hospice were males. Freestanding hospices had the lowest percent of black patients at 5 percent whereas black persons comprised 12 percent of the SNF based hospice enrollment.

Patient Mortality

The election of the hospice benefit is predicated on a prognosis of terminal disease, usually cancer. However, there is room for error in such determinations and there is bound to be some variation in how long persons survive before dying. Table 3-4 shows the cumulative mortality rate following hospice election for Medicare hospice enrollees. Almost one-fifth of enrollees (18.9 percent) die within 1 week of enrollment. At 2 weeks postenrollment one-third of persons have died. The median survival time is

about 1 month, and by 3 months about four-fifths of enrollees have died. By the end of 1 year following hospice enrollment, slightly more than 5 percent of persons remain alive, and 2.6 percent survive for 2 years or more. Although the surviving patients are few in number, they are likely to account for a disproportionately large amount of hospice expenditures as well as basic Part A and Part B Medicare expenditures (see expenditure section below).

There is a remarkable consistency in mortality rates across all age, sex, and race groupings. This probably indicates that the terminal nature of the underlying disease is the preeminent factor in postenrollment mortality. There is no additional mortality associated with age, sex or race.

3.2 Growth in Number and Size of Hospices

Program growth can also be measured in terms of the number and size of participating hospice facilities. Hospice size is defined here in terms of the number of Medicare beneficiaries enrolled per year. The total case load for any hospice could be much larger. Table 3-5 shows the distribution of facilities by number of Medicare hospice beneficiaries for the years 1987 through 1989. In 1987 the nearly 34,000 Medicare beneficiaries were served by 428 Medicare certified hospices. The average number of hospice beneficiaries per facility was 79. Seven facilities (2 percent of the total) each had over 500 Medicare patients, for an average of 873 patients. These seven facilities accounted for 18 percent of all Medicare patients treated in 1987. At the other end of the size spectrum were 84 facilities who had fewer than 10 Medicare patients each. Twenty percent all facilities were this size and they only accounted for 1 percent of all Medicare patients.

The distribution by facility size was similar in 1989. Two percent of the 760 facilities accounted for 18 percent of all Medicare patients. Very small facilities (i.e., less than 10 patients) were now 13 percent of all facilities and still only accounted for 1 percent of all Medicare patients. The average size of facility increased from 79 Medicare patients per facility in 1987 to 88 Medicare patients per facility in 1989.

Of course, it is not necessarily the same facilities which appear in each size category in each year. In fact, the very small Medicare case load facilities tend to be the newest facilities (in terms of Medicare certification) and they expand very quickly. This is shown in Table 3-6 which arrays facility size holding constant their size in 1987. For example, as shown in Table 3-5 there were 7 facilities with at least 500 patients each who served a total of 6,110 patients in 1987. In 1988 those same 7 facilities served a total of 7,196 patients. These 7 facilities increased their patient load from 873 patients per facility in 1987 to 1,068 patients per facility in 1989. There was an increase in patients served in all size groupings, indicating that some of the growth in the program was due to extant hospices increasing their individual patient loads.

Of particular interest is the group of 332 hospices which either were not certified in 1987 and/or did not serve any Medicare beneficiaries. By 1989 these hospices were providing services to 14,551 Medicare beneficiaries. Looked at another way, 44 percent of the growth in the hospice program from 1987 to 1989 is due to new hospices entering the program and providing services. On the other hand, 56 percent of program growth during this period was due to increased patient load among already existing hospices.

This indicates a very dynamic situation within the hospice community. Although there are many hospices with very few Medicare patients, the recent experience shows that those hospices tend to increase their Medicare case load rapidly and are thus unlikely to face the same financial pressures from expensive outlier patients in subsequent years as they do in the early phase of Medicare participation.

3.3 Hospice Expenditures

Hospice expenditures are, in part, a product of the length of the hospice stay times the relative mix of types of hospice days and the payment rate for each of those days. In addition, there are payments for hospice physician services. This, however, represents only the hospice portion of Medicare's expense for these patients.

Although a patient who elects the hospice benefit forfeits basic Part A and Part B benefits for the terminal illness, he/she retains coverage for unrelated conditions. Attending physician[4] services are still covered for these patients, if the attending physician is not an employee of, or receiving compensation from the hospice. Attending physician services are not considered hospice care. Further, a patient can have up to three hospice benefit periods thus potentially interrupting the hospice portion of care. Some patients also exhaust the 210 day limitation[5] and return to Medicare Part A and Part B coverage.

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[4] The term "attending physician" means the physician who is identified by the beneficiary as having the most significant role in the determination and delivery of medical care to the beneficiary at the time he or she elects to receive hospice care. This physician may, but need not, be employed by the hospice. If employed by the hospice, services rendered by the attending physician are considered to be hospice physician services and are paid accordingly.

[5] The 210 day limitation was removed by OBRA 1990, enacted November 1990, retroactive to January 1, 1990.

Therefore, in order to get a true picture of the total expenditure by Medicare for hospice patients, it is necessary to combine all expenditures, both hospice and Part A and Part B services incurred after election of the hospice benefit. However, it is not possible to infer from the data the intent behind the changes in coverage. For example, the decision to terminate the hospice benefit could be due to a patient's desire to receive services not normally provided under the hospice benefit (such as surgery or radiation therapy), or due to the patient going into remission. It could also be due to factors unrelated to the course and treatment of illness, such as a change in residence.

Expenditures were analyzed by linking the hospice enrollment file with the Medicare Automated Data Retrieval System (MADRS). MADRS is a system for retrieval of bill records for any group of Medicare beneficiaries. It includes 100 percent of all bills, Part A, Part B, and hospice. The linkage was done on the basis of the hospice enrollment date. That is, only records for which the start date of the bill was subsequent to the hospice enrollment date were included. For example, many hospice enrollments are apparently made during a Part A hospital stay. Because the admission date for these stays precedes the hospice enrollment date, these admission were excluded from the analysis. All hospital stays that began after the hospice enrollment date were included. The same inclusion criteria were used for all outpatient, skilled nursing facility, home health agency and physician services in sites other than a physician's office. Bills for physician care in the physician's office are summarized by calendar year.

Office based physician care payments were prorated according to the date of hospice enrollment. Because physician payments were higher in the period prior to hospice enrollment, only one-half of the prorated amount was estimated as post-hospice enrollment.[4] For example, a patient whose enrollment date was November 1, 1987, would have one-twelfth of the 1987 physician office payments assigned to the post-hospice enrollment period, as well as 100 percent of physician office payments for 1988 and 1989.

Not all persons who elected the hospice benefit actually used hospice services. Many apparently die before being discharged from the hospital. There may be others who

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[4] A sensitivity analysis showed that physician office costs per day in the pre-enrollment period were roughly twice the rate of the post-enrollment period. Using the prorating formula, Part B in office expenditures accounted for 2 percent of post-hospice enrollment Medicare expenditures. Therefore, errors in the accuracy of the prorating estimation are unlikely to affect the results of these analyses to any great degree.

revoke the benefit before using any services. The analyses that follow are limited to only those persons who received at least 1 day of hospice service.

Table 3-7 shows the basic daily payment rates for hospice care since the program's inception in 1983. Beginning in that year the rates for routine, continuous,[7] inpatient respite, and general inpatient care were $46.25, $358.67, $55.33, and $271.00, respectively. In 1985, the routine rate was increased to $53.17, the others remaining the same. There was a $10 per day increase in 1986 for all types of hospice days. These rates remained in effect until 1990 when there was a 20 percent increase for all day rates. There was another 5.2 percent increase in October of 1990 for all services. The current legislation calls for annual inflation adjustments. Compared to the original 1983 rates, the current rates in 1991 are about 30 percent higher for general inpatient and continuous care, 49 percent higher for inpatient respite, and 72 percent higher for routine care.

Table 3-7 also shows the estimated effect of these rate changes on an illustrative hospice stay of 40 days. In 1984 Medicare expenditures for a 40-day stay would have been $2,298. Currently, Medicare expenditures for a hospice stay with the same mix of days would be $3,738, a 63 percent increase. The increase is due largely to the routine care day rate increases because routine care days account for 95 percent of all hospice days.

The actual Medicare expenditures for a hospice stay are more complicated than the illustration above. Expenditures depend both on the length of stay and the relative mix of types of days provided. Both length of stay and mix of days have been changing.

Table 3-8 shows the length of hospice stay, by hospice type, for the time period 1987 through the second quarter of 1989.[8] For all hospice patients enrolled in the first quarter of 1987, the average length of hospice stay was 38.5 days. This increased in each subsequent quarter up to 47.9 days for the second quarter of 1989, an increase of 9.4 days, or 24 percent. The increases were not consistent across hospice types. In the first quarter of 1987 there was less than a day difference in length of stay across these hospice types. Freestanding facilities experienced the largest stay increase (12 days) and had reached a 50.8 day length of hospice stay by the second quarter of 1989, the

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[7] Continuous care is paid on an hourly basis with a minimum use of 8 hours in a day. The rate in Table 7 is for a 24 hour day.

[8] The enrollment file update was not sufficiently recent to allow adequate followup on patients enrolled after June of 1989.

longest of any type of hospice. Hospital based and home health based hospices experienced more moderate increases of 8.7 days and 7.5 days, respectively. SNF based hospices, however, showed essentially no change during this time period. Due to the relatively small enrollments for SNF based hospices the quarterly lengths of stay tend to vary quite a bit. Still, there is no discernable trend in length of hospice stay for this type of hospice and by the middle of 1989 the length of stay for this type of hospice was about 10 days less than the overall average.

There has been a shift from the more expensive general inpatient and continuous care days to the less expensive routine care days. Average hospice covered charges by type of service and type of hospice are shown in Table 3-9. In 1987 and 1988 the average total charge per patient was $3,255 and $3,697, respectively. Routine care days accounted for 80.5 percent of charges in 1987, increasing to 83.7 percent in 1988. General inpatient care decreased from 16.1 percent of the total in 1987 to 13.8 percent in 1988. Continuous care, although not a major component in either year also experienced a decline, from 2.2 percent of charges in 1987 to 1.5 percent in 1988. The most striking change occurred among SNF based hospices where general inpatient care decreased from 34 percent of covered charges in 1987 to 24.7 percent in 1988. Due to the rapid influx of new hospice providers it is not apparent how much of the changes are due to an overall change in treatment patterns versus entry of new providers with different treatment patterns.

Average hospice payments, Medicare Part A and Part B payments and average lengths of stay by type of hospice are shown for the years 1987 and 1988 in Tables 3-10, 3-11, and 3-12. Table 3-10 shows the rates for persons who lived less than 90 days from the date of hospice enrollment, Table 3-11 shows the rates for persons who lived longer than 90 days, and Table 3-12 shows the rates for all persons combined.

There was very little difference between 1987 and 1988 in the use of hospice care by persons who lived less than 90 days (Table 3-10). For all types of facilities combined, the average length of stay (for persons living 90 days or less) was 23.3 days in 1987 and 23.7 days in 1988. This accounted for over 90 percent of the total days of life in both years. The average hospice payment amount in both years was just under $2,000. Nonhospice Part A and Part B expenditures in both years was just under $600, making the total Medicare expenditures for these patients $2,576 in 1987 and $2,579 in 1988. There was a notable change in treatment patterns for SNF based hospices. Average length of stay decreased by 1.3 days, from 22.6 days in 1987 to 21.3 days in 1988. However, due to a shift from general inpatient days to routine care days (see Table 3-9) the average hospice charge was reduced by $456 per patient, a 16 percent reduction. Because Part A and Part B expenditures remained essentially unchanged, the total average Medicare expenditures for SNF based hospice patients declined by a similar amount.

A different pattern of care is shown for patients whose life extended beyond 90 days (Table 3-11). For all facilities combined, in 1987 these patients averaged 105.5 days of hospice care out of a total life span of 306.3 days. Thirty-four percent of their post-hospice enrollment life span was spent in hospice care. For persons whose hospice election occurred in 1988 the average hospice stay was 124.2 days, out of a life span of 272.7 days, or 46 percent of the post-enrollment life span. The longer hospice stay increased hospice payments from $7,685 per person in 1987 to $9,809, a 28 percent increase. Other Medicare Part A and Part B expenditures decreased by almost $900, from $4,899 per person to $4,008, an 18 percent decrease. Total Medicare expenditures for these persons increased by over $1,200, from $12,584 in 1987 to $13,817 in 1988. In both 1987 and 1988, persons living longer than 90 days accounted for 21 percent of all hospice enrollees. In 1987 they accounted for 54 percent of hospice expenditures and 57 percent in 1988.

The change in treatment for persons living longer than 90 days was different for each type of hospice. For hospital based hospices, the 14 percent increase in hospice expenditures was matched by a 24 percent decline in Part A and Part B expenditures so that the total Medicare payments remained virtually unchanged at just under $12,200 per person. For SNF based hospices there was a slight 5 percent increase in hospice expenditures but no change in Part A and Part B expenditures. In both 1987 and 1988, total per capita Medicare expenditures were highest for this type of hospice, even though they had the shortest life expectancy following hospice enrollment.

The greatest increase in expenditures was experienced by persons electing freestanding hospices. There was a 20 percent increase in hospice days from 1987 to 1988. However, due to a shift from routine days to general inpatient days, average hospice expenditures increased by 35 percent, from $7,587 to $10,267. This was only partially offset by a $700 decrease in Part A and Part B expenditures. Therefore, the average Medicare expenditures for patients in freestanding hospices increased from $12,060 in 1987 to $14,051, a 16 percent increase.

Table 3-12 shows the Medicare expenditures for all hospice patients regardless of length of life following hospice enrollment. The average Medicare payment per person for hospice care increased by 14 percent, from $3,168 to $3,623, a 14 percent increase. This was partially offset by an 11 percent decline in Part A and Part B expenditures so that the total cost to Medicare per hospice patient increased by 6 percent, from $4,641 in 1987 to $4,931 in 1988. There was little change in Medicare expenditures per patient for hospital and home health-based hospice patients. SNF based patients were the most expensive in 1987 at $5,120 and the least expensive in 1988 at $4,484. This was largely a length of hospice stay and length of life (post-enrollment) effect. On a per day basis, SNF based patients were the most expensive hospice patients in both years.

The course of a hospice stay is not the same for all persons. A number of events can occur to lengthen (or shorten) the stay. For example, the patient may decide to withdraw from the benefit and return to basic Medicare coverage, perhaps electing the benefit at a later date, perhaps not. Although most people who elect the benefit die while covered under the benefit, many terminate their hospice election and die under Medicare Part A and Part B coverage.

Table 3-13 shows hospice expenditures and length of stay as well as Part A and Part B expenditures by type of stay and type of hospice. The types of stays represent mutually exclusive and exhaustive categories:

- Group (#1) persons elect the benefit and receive hospice care continuously until death, representing about two-thirds of all hospice enrollees.

- Group (#2) persons have continuous hospice coverage from election until death but, for one reason or another, do not receive continuous hospice care. About one out of six hospice patients have this experience.

- Group (#3) persons have multiple hospice coverage periods with some gaps (when Medicare Part A and Part B are in effect) between coverage periods. They also die while under the benefit, but the coverage is not continuous. Two percent fit this pattern.

- Group (#4) includes those patients who die under Part A and Part B coverage and terminate benefits before reaching the 210 day limit. They represent 13 percent of all hospice enrollees.[9]

- Group (#5) consists of those patients who die under Part A and Part B coverage after exhausting the maximum hospice benefit.[10] Two percent of patients were in this category.

In 1988 group #1 averaged 29.9 days of hospice care, which, due to the definition of this group, is exactly equal to their length of life from hospice election. Per capita

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[9] It is possible for persons in this group also to have had gaps in coverage.

[10] The 210 day limit was eliminated in 1989. Thus some people who elected the benefit in 1988 used more than 210 days because their coverage extended into 1989. Anyone who used 210 or more days and then terminated benefits were counted in this category.

hospice expenditures were $2,439 with an additional $370 in Part A and Part B expenditures for a total average Medicare expenditure of $2,809. Part A and Part B expenditures account for 13 percent of Medicare's payments for these patients. Group #2 received an average of 47 days of hospice care, 76 percent of the total of 69.1 days of life from hospice election. Total Medicare expenditures for this group were $4,901, of which 30 percent ($1,455) were for Part A and Part B expenditures.

Those persons who had a gap in coverage but still died under the benefit (group #3) had a length of life of about one-half year (180.2 days), during which they received 90.8 days of hospice care. The average Medicare expenditure for this group was $11,328. Part A and Part B expenditures account for 44 percent of total expenditures.

Those who died outside of the benefit without exhausting the 210 day limit (group #4) also had a level of Part A and Part B expenditures which exceeded 40 percent of the total post-enrollment Medicare expenditure level ($5,334 out of $12,593). Those who exhausted the benefit, however, had relatively lower Part A and Part B expenditures ($2,618) even though they had over 200 days of nonhospice coverage from the election date until death. It appears therefore, that groups #3 and #4 were choosing, at various points in time, to elect the more traditional set of health services in place of the palliative hospice care. These persons incur the most Medicare expenditures, in aggregate, of hospice patients, but they are the least expensive per day of life from hospice enrollment to death. Groups #3 and #4 account for 15 percent of all hospice enrollees, yet account for 29 percent of all hospice expenditures and 59 percent of all post-enrollment Part A and Part B expenditures.

However, when assessed on the basis of expenditures per day of life from hospice enrollment, those who disenrolled have much lower average daily total Medicare expenditures ($58, $45 and $54 respectively for groups 3, 4, and 5) than the hospice patients in categories #1 and #2 ($94 and $80 respectively), who died while enrolled in the hospice benefit. It does not appear that, on average, those hospice patients who disenrolled from hospice obtained much expensive care outside the hospice, contrary to concern that some number of hospice patients who need high cost care and/or their providers must "game" the system by revoking the hospice election and getting the care through regular Medicare benefits.

Table 3-13 also shows the aggregate Medicare expenditures for the 47,171 persons who enrolled in hospice in 1988. The Medicare expenditures for these persons were $170.9 million for hospice care, and $61.7 million for Part A and Part B expenditures, for total Medicare expenditures of $232.6 million. On the basis of days of life from hospice election, all hospice enrollees averaged $63.71 per day in 1988. This is very similar to the hospice routine home care rate in effect at the time, $63.17, that was Congressionally raised to $79.94 for FY 1991. Since the groups that disenrolled had lower per capita Medicare expenditures per day of life than the first two groups that

did not disenroll, it appears that those disenrollees could have been cared for, on average, under the hospice benefit, but would likely have resulted in higher total Medicare expenditures.

Table 3-1
Trends in Demographic Characteristics of the
Medicare Hospice population: 1983 to 1989

	1983		1984		1985		1986		1987		1988		1989	
	N	Pct	N	Pct	N	Pct	N	Pct	N	Pct	N	Pct	N	Pct
Total	135	(100)	4,981	(100)	13,615	(100)	21,153	(100)	33,841	(100)	49,964	(100)	66,584	(100)
Lt 65	7	(5)	326	(7)	805	(6)	1,219	(6)	1,894	(6)	2,655	(5)	3,577	(5)
65 to 69	38	(28)	1,132	(23)	2,961	(22)	4,676	(22)	7,210	(21)	10,216	(20)	13,351	(20)
70 to 74	36	(27)	1,257	(25)	3,379	(25)	5,145	(24)	8,085	(24)	11,708	(23)	15,118	(23)
75 to 79	24	(18)	1,085	(22)	2,934	(22)	4,606	(22)	7,280	(22)	10,804	(22)	14,502	(22)
80 to 84	16	(12)	684	(14)	2,030	(15)	3,154	(15)	5,212	(15)	8,091	(16)	10,814	(16)
85+	14	(10)	497	(10)	1,506	(11)	2,353	(11)	4,160	(12)	6,490	(13)	9,222	(14)
Male	51	(38)	2,514	(50)	7,049	(52)	11,167	(53)	17,859	(53)	26,151	(52)	34,943	(52)
Female	84	(62)	2,467	(50)	6,566	(48)	9,986	(47)	15,982	(47)	23,813	(48)	31,641	(48)
White	119	(88)	4,403	(88)	12,246	(90)	19,100	(90)	30,457	(90)	44,819	(90)	59,513	(89)
Black	10	(7)	378	(8)	847	(6)	1,295	(6)	2,110	(6)	3,192	(6)	4,367	(7)
Oth/Unk	6	(4)	200	(4)	522	(4)	758	(4)	1,274	(4)	1,953	(4)	2,704	(4)
OASI	128	(95)	4,705	(94)	12,969	(95)	20,117	(95)	32,246	(95)	47,619	(95)	63,374	(95)
Disability	7	(5)	272	(5)	626	(5)	1,009	(5)	1,539	(5)	2,276	(5)	3,082	(5)
Renal	0	(0)	4	(0)	20	(0)	27	(0)	56	(0)	69	(0)	128	(0)
ESRD	0	(0)	17	(0)	75	(1)	108	(1)	218	(1)	293	(1)	443	(1)
Not ESRD	135	(100)	4,964	(100)	13,540	(99)	21,045	(99)	33,623	(99)	49,671	(99)	66,141	(99)

Table 3-2
Medicare Hospice Enrollment and Hospice Certification by State; 1989

State	1989 Enrollment	Est Per. of Cancer Deaths	Number of Cert. Hosp	Est Per. of NHO Guide
Alabama	1,233	22%	21	72%
Alaska	2	3%	0	0%
Arizona	916	22%	9	53%
Arkansas	526	12%	15	---
California	4,862	17%	56	44%
Colorado	1,369	61%	23	100%
Connecticut	1,096	23%	6	22%
Delaware	390	46%	3	43%
District of Col.	120	11%	3	---
Florida	12,041	38%	33	94%
Georgia	1,073	18%	21	78%
Hawaii	267	37%	4	50%
Idaho	359	38%	9	75%
Illinois	2,788	18%	29	45%
Indiana	335	5%	7	22%
Iowa	628	13%	14	33%
Kansas	455	12%	4	13%
Kentucky	1,599	30%	18	72%
Lousiana	1,213	25%	17	94%
Maine	45	2%	1	10%
Maryland	546	11%	12	34%
Massachusetts	1,861	19%	23	55%
Michigan	2,233	21%	29	40%
Minnesota	1,047	19%	15	28%
Mississippi	177	5%	4	57%
Missouri	1,348	16%	19	59%
Montana	216	22%	4	29%
Nebraska	230	9%	7	44%
Nevada	408	41%	2	40%
New Hampshire	62	4%	1	6%
New Jersey	3,098	26%	27	77%
New Mexico	419	36%	9	100%
New York	3,988	14%	39	93%
North Carolina	2,215	29%	42	64%
North Dakota	164	17%	4	50%
Ohio	3,059	21%	39	59%
Oklahoma	398	8%	8	57%
Oregon	625	16%	8	28%
Pennsylvania	2,353	11%	40	47%
Rhode Island	439	23%	5	71%
South Carolina	422	13%	8	50%
South Dakota	93	9%	4	33%
Tennessee	885	13%	17	61%
Texas	4,836	33%	35	74%
Utah	79	10%	1	14%
Vermont	96	14%	6	67%
Virginia	588	9%	5	19%
Washington	1,091	21%	18	60%
West Virginia	471	15%	6	50%
Wisconsin	1,440	21%	24	63%
Wyoming	15	5%	1	50%
United States	66,219	20%	756	47%

Table 3-3

Medicare Hospice Enrollment by Type of Hospice: 1987-1989

	Hospital N (Pct)	SNF N (Pct)	Home Health N (Pct)	Freestanding N (Pct)	Total[1] N (Pct)
Total	24,611(100)	4,708(100)	57,640(100)	63,206(100)	150,231(100)
Lt 65	1,447 (6)	243 (5)	3,030 (5)	3,384 (5)	8,109 (5)
65 to 69	5,299 (22)	983 (21)	11,812 (20)	12,637 (20)	30,746 (20)
70 to 74	5,741 (23)	1,063 (23)	13,459 (23)	14,606 (23)	34,882 (23)
75 to 79	5,249 (21)	1,040 (22)	12,511 (22)	13,732 (22)	32,550 (22)
80 to 84	3,863 (16)	758 (16)	9,022 (16)	10,445 (17)	24,096 (16)
85 +	3,012 (12)	621 (13)	7,806 (14)	8,402 (13)	19,848 (13)
Male	12,939 (53)	2,303 (49)	29,526 (51)	34,069 (54)	78,877 (53)
Female	11,672 (47)	2,405 (51)	28,114 (49)	29,137 (46)	71,354 (47)
White	21,492 (87)	4,016 (85)	51,395 (89)	57,713 (91)	134,670 (90)
Black	1,898 (8)	555 (12)	3,983 (7)	3,196 (5)	9,640 (6)
Oth/Unk	1,221 (5)	137 (3)	2,262 (4)	2,297 (4)	5,921 (4)
OASI	23,011 (95)	4,459 (95)	54,365 (95)	59,623 (95)	141,519 (95)
Disability	1,231 (5)	220 (5)	2,571 (5)	2,846 (5)	6,873 (5)
Renal	43 (0)	4 (0)	108 (0)	98 (0)	253 (0)
ESRD	145 (1)	15 (0)	397 (1)	388 (1)	946 (1)
Not ESRD	24,140 (99)	4,668(100)	56,647 (99)	62,179 (99)	147,699 (99)

[1] The totals in this table do not equal those of Table 1 because a number of patients who elected the hospice benefit either died before using any hospice benefits or the hospice type indicator was missing.

Table 3-4
Hospice Patient Mortality, from Enrollment Date
by Age, Sex, Race and Year of Enrollment

	Days from Enrollment									N
	7	14	21	28	60	91	181	365	730	
Total	18.9%	33.1%	43.0%	50.5%	70.2%	79.0%	89.2%	94.7%	97.4%	218,580
Lt 65	16.7	28.5	37.1	44.0	63.4	72.8	85.5	92.8	96.2	11,983
65-69	18.8	33.6	44.0	51.7	72.3	81.2	91.1	96.0	98.0	45,268
70-74	19.0	33.6	43.7	51.4	71.8	80.8	90.7	95.7	98.0	50,916
75-79	18.7	33.2	43.2	50.7	70.3	79.2	89.6	95.0	97.7	47,530
80-84	19.1	32.7	42.5	50.0	69.0	77.7	88.1	94.0	97.1	34,646
85 +	20.1	34.0	43.2	50.1	68.0	76.1	85.8	92.1	96.1	28,237
Male	20.1	35.0	45.4	52.9	72.3	80.8	90.4	95.5	97.9	114,509
Female	17.6	31.1	40.5	47.9	67.8	77.0	87.9	93.9	96.9	104,071
White	19.1	33.5	43.4	50.9	70.4	79.2	89.3	94.8	97.5	195,889
Black	17.0	30.5	40.2	47.4	67.3	76.6	87.8	93.9	96.9	14,075
Unknown	15.6	27.3	36.5	44.5	66.9	77.1	88.6	94.5	97.1	5,908
Other	20.6	36.2	45.8	53.6	72.6	79.7	88.9	94.6	97.1	2,708
1983	10.4	23.7	34.8	40.7	60.0	67.4	85.9	93.3	96.3	135
1984	17.6	31.4	41.0	48.7	69.4	78.7	89.9	95.4	98.0	4,987
1985	19.1	33.7	43.8	51.3	71.6	80.4	90.6	95.5	97.9	13,605
1986	18.7	33.4	43.6	51.1	71.1	80.1	90.4	95.6	98.1	21,140
1987	18.9	33.5	43.8	51.3	71.3	80.3	90.1	95.2	97.7	33,819
1988	18.9	33.1	42.9	50.7	70.7	79.6	89.7	95.0	98.0	49,948
1989	18.8	32.9	42.7	50.1	69.6	78.5	88.5	94.2	94.2	66,466

Table 3-5
Hospice Facility Size: 1987 to 1989
Number of Medicare Beneficiaries Served

Size[1]	1987 Facilities	1987 Patients	1987 Average	1988 Facilities	1988 Patients	1988 Average	1989 Facilities	1989 Patients	1989 Average
500+	7 (2)	6,110 (18)	873	12 (2)	9,885 (20)	824	13 (2)	11,814 (18)	909
200-499	27 (6)	7,864 (23)	291	45 (8)	12,140 (24)	270	56 (7)	16,721 (25)	299
100-199	59 (14)	8,845 (26)	150	85 (14)	12,194 (24)	143	117 (15)	16,702 (25)	143
50-99	89 (21)	6,264 (19)	70	129 (22)	9,100 (18)	71	173 (23)	12,459 (19)	72
25-49	90 (21)	3,221 (10)	36	119 (20)	4,193 (8)	35	167 (22)	6,144 (9)	37
10-24	72 (17)	1,201 (4)	17	122 (20)	2,029 (4)	17	137 (18)	2,319 (3)	17
1-9	84 (20)	336 (1)	4	85 (14)	424 (1)	5	97 (13)	426 (1)	4
Total	428(100)	33,841(100)	79	597(100)	49,965(100)	84	760(100)	66,585(100)	88

[1] Size is the number of Medicare beneficiaries served in that year.

Table 3-6
Change in Size of Hospices; by number of Medicare Beneficiaries in 1987

Size[1]	Facilities	1987		1988		1989		Increase	Percent of Total Increase
		Patients	Average	Patients	Average	Patients	Average		
500+	7	6,110	873	7,196	1,028	7,475	1,068	1,365	4%
200-499	27	7,864	291	9,344	346	10,951	406	3,087	9%
100-199	59	8,845	150	11,063	188	11,577	196	2,732	8%
50-99	89	6,264	70	8,342	94	9,194	103	2,930	9%
25-49	90	3,221	36	4,972	55	5,997	67	2,776	8%
10-24	72	1,201	17	2,607	36	3,201	44	2,000	6%
1-9	84	336	4	2,249	27	3,639	43	3,303	10%
0	332	0	0	4,192	13	14,551	44	14,551	44%
Total	760	33,841	73	49,965	84	66,585	88	32,744	100%

[1] Size is based on the number of Medicare beneficiaries served in 1987.

Table 3-7
Hospice Reimbursement Rates

Type	From: / To:	11/01/83 12/31/84	01/01/85 03/31/86	04/01/86 12/31/89	01/01/90 09/30/90	10/01/90 Present
Routine		$ 46.25	$ 53.17	$ 63.17	$ 75.80	$ 79.74
Continuous(24hrs)		$358.67	$358.67	$368.67	$442.40	$465.40
Inp Respite		$ 55.33	$ 55.33	$ 65.33	$ 78.40	$ 82.48
General Inp		$271.00	$271.00	$281.00	$337.20	$354.73
Estimated 40 day stay[1]		$2,298	$2,561	$2,961	$3,553	$3,738

[1] The 40 day estimate is based on the relative distribution of days used in 1988. In that year 95 percent of days were routine care, 4 percent were general inpatient, 0.7 percent were continuous care, and 0.3 percent were inpatient respite. Hospice physician payments are not included.

Table 3-8
Length of Hospice Stay by Type of Hospice
1987 to 1989

Year/ Quarter	Type of Hospice									
	Hospital		SNF		Home Health		Freestanding		Total	
	N	LOS	N	LOS	N	LOS	N	LOS	N	LOS
87-1st	605	37.9	214	38.3	2,056	38.3	2,723	38.8	5,598	38.5
87-2nd	580	40.0	224	40.7	2,118	38.2	2,739	41.1	5,661	39.9
87-3rd	682	43.9	241	39.3	2,422	39.1	2,990	43.2	6,335	41.6
87-4th	921	40.9	256	36.6	2,987	38.3	3,267	43.1	7,431	40.7
88-1st	1,084	45.0	322	32.3	3,566	40.4	3,767	43.8	8,739	42.1
88-2nd	1,368	43.2	346	32.1	3,943	42.2	4,120	45.7	9,777	43.5
88-3rd	1,581	42.8	294	42.5	4,367	43.6	4,731	47.5	10,973	45.1
88-4th	1,737	45.2	321	33.8	4,390	44.7	4,789	49.6	11,237	46.6
89-1st	2,223	44.5	344	36.8	4,757	46.6	5,477	50.2	12,801	47.5
89-2nd	2,277	46.5	329	37.1	4,790	45.8	5,744	50.8	13,140	47.9
Change		8.7		-1.2		7.5		12.0		9.4
Pct chg		23%		-3%		19%		31%		24%

Table 3-9
Covered Hospice Charges by Type of Service
By Type of Hospice: 1987-1988

Year	Persons	Hospice Service					
		Total	Routine	Inpat	Phys	Resp	Cont
				Hospital Based			
1987	3,025	$3,373	$2,579	$723	$9	$17	$48
		100.0%	76.4%	21.4%	0.3%	0.5%	1.4%
1988	6,422	$3,682	$2,877	$742	$14	$22	$29
		100.0%	78.1%	20.1%	0.4%	0.6%	0.8%
				SNF Based			
1987	1,132	$4,031	$2,460	$1,372	$109	$21	$69
		100.0%	61.0%	34.0%	2.7%	0.5%	1.7%
1988	1,522	$3,489	$2,505	$862	$66	$23	$32
		100.0%	71.8%	24.7%	1.9%	0.7%	0.9%
				Home Health Based			
1987	11,148	$3,343	$2,565	$675	$39	$8	$43
		100.0%	76.7%	20.2%	1.2%	0.2%	1.3%
1988	18,960	$3,720	$3,025	$598	$40	$9	$41
		100.0%	81.3%	16.1%	1.1%	0.2%	1.1%
				Freestanding Based			
1987	13,637	$3,093	$2,686	$287	$17	$6	$97
		100.0%	86.9%	9.3%	0.6%	0.2%	3.1%
1988	20,267	$3,696	$3,271	$325	$15	$7	$80
		100.0%	88.5%	8.8%	0.4%	0.2%	2.2%
				Total			
1987	28,942	$3,255	$2,619	$525	$28	$8	$70
		100.0%	80.5%	16.1%	0.9%	0.3%	2.2%
1988	47,171	$3,697	$3,094	$509	$27	$10	$56
		100.0%	83.7%	13.8%	0.7%	0.3%	1.5%

Table 3-10
Hospice, Part A and Part B, and Total Medicare Expenditures
By Hospice Type: 1987 and 1988
Persons Living 90 days or Less

Year	No. of Persons	Days		Per Capita Expenditures		
		Hosp	Life	Hospice	Part A/B	Total
				Hospital Based		
1987	2,350	23.5	26.8	$2,023($ 86)	$529	$2,552($ 95)
1988	4,984	24.6	26.8	2,135(87)	505	2,640(99)
87-88	112%	5%	0%	6%	-5%	3%
				SNF Based		
1987	945	22.6	23.9	2,791(123)	430	3,221(135)
1988	1,312	21.3	22.7	2,334(110)	429	2,763(122)
87-88	39%	-6%	-5%	-16%	0%	-14%
				Home Health		
1987	8,903	22.5	25.0	2,033(90)	650	2,684(107)
1988	15,148	23.3	25.3	2,034(87)	643	2,677(106)
87-88	70%	3%	1%	0%	-1%	0%
				Freestand		
1987	10,771	24.0	25.9	1,885(79)	551	2,435(94)
1988	15,856	24.1	26.1	1,865(77)	586	2,451(94)
87-88	47%	0%	1%	-1%	6%	1%
				Total		
1987	22,969	23.3	25.6	1,994(86)	582	2,576(101)
1988	37,300	23.7	25.8	1,986(84)	593	2,579(100)
87-88	62%	2%	1%	0%	2%	0%

Table 3-11
Hospice, Part A and Part B, and Total Medicare Expenditures
By Hospice Type: 1987 and 1988
Persons Living 91 days or More

Year	No. of Persons	Days		Per Capita Expenditures		
		Hosp	Life	Hospice	Part A/B	Total
				Hospital		
1987	675	104.1	297.6	$7,502 ($ 72)	$4,692	$12,195($ 41)
1988	1,438	114.3	279.3	8,583 (75)	3,584	12,167(44)
87-88	113%	10%	-6%	14%	-24%	0%
				SNF		
1987	187	111.9	270.5	10,250(92)	4,469	14,719(54)
1988	210	124.3	245.4	10,749(86)	4,484	15,233(62)
87-88	12%	11%	-9	5%	0%	4%
				Home Health		
1987	2,245	102.0	309.1	7,652(75)	5,538	13,191(43)
1988	3,812	121.3	270.8	9,689(80)	4,401	14,090(52)
87-88	70%	19%	-12%	27%	-21%	7%
				Freestand		
1987	2,866	108.2	308.5	7,587(70)	4,474	12,060(39)
1988	4,411	130.0	273.5	10,267(79)	3,784	14,051(51)
87-88	54%	20%	-11%	35%	-16%	16%
				Total		
1987	5,973	105.5	306.3	7,685(73)	4,899	12,584(41)
1988	9,871	124.2	272.7	9,809(79)	4,008	13,817(51)
87-88	65%	18%	-11%	28%	-18%	10%

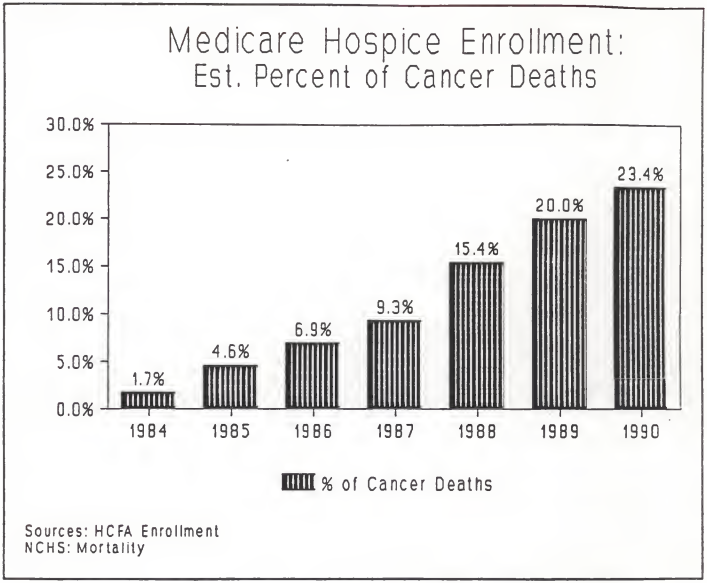
Table 3-12
Hospice, Part A and Part B, and Total Medicare Expenditures
By Hospice Type: 1987 and 1988
All Hospice Enrollees

Year	No. of Persons	Days		Per Capita Expenditures		
		Hosp	Life	Hospice	Part A/B	Total
				Hospital		
1987	3,025	41.5	87.2	$3,246 ($ 78)	$1,458	$4,704($ 54)
1988	6,422	44.7	83.3	3,579 (80)	1,194	4,773(57)
87-88	112%	8%	-4%	10%	-18%	1%
				SNF		
1987	1,132	37.4	64.7	4,023 (108)	1,097	5,120(79)
1988	1,522	35.5	53.4	3,495 (98)	989	4,484(84)
87-88	34%	-5%	-17%	-13%	-10%	-12%
				Home Health		
1987	11,148	38.6	82.2	3,165 (82)	1,635	4,800(58)
1988	18,960	43.0	74.7	3,573 (83)	1,399	4,972(67)
87-88	70%	11%	-9%	13%	-14%	3%
				Freestand		
1987	13,637	41.7	85.3	3,083 (74)	1,375	4,458(52)
1988	20,267	47.1	79.9	3,693 (78)	1,282	4,975(67)
87-88	49%	13%	-6%	20%	-7%	12%
				Total		
1987	28,942	40.3	83.5	3,168 (79)	1,473	4,641(56)
1988	47,171	44.8	77.4	3,623 (81)	1,307	4,931(64)
87-88	63%	11%	-7%	14%	-11%	6%

Table 3-13
Hospice Patient Expendituress by Enrollment Experience
and Hospice Type 1988

	N	Days		Per Capita Expenditures			Total Expenditures (in $1,000s)		
		Hosp	Life	Hospice	Part A/B	Total	Hospice	Part A/B	Total
Hospital Based									
TotHosp	4,177	31.0	31.0	$2,630($ 85)	$342	$2,972($ 96)	$10,986	$1,429	$12,414
No Cap	1,187	41.8	57.9	$3,112(74)	$1,210	$4,322(75)	$3,694	$1,436	$5,130
With gap	113	89.3	241.4	$5,689(64)	$4,622	$10,311(43)	$643	$522	$1,165
Post-lt 210	855	96.9	319.5	$7,049(73)	$4,681	$11,730(37)	$6,027	$4,002	$10,029
Post 210+	90	210.4	406.1	$18,159(86)	$3,105	$21,264(52)	$1,634	$279	$1,914
Total	6,422	45.3	83.3	$3,579(79)	$1,194	$4,773(57)	$22,984	$7,669	$30,652
SNF Based									
TotHosp	1,251	27.2	27.2	$2,788(103)	$297	$3,085(113)	$3,488	$372	$3,859
No Cap	126	37.4	53.8	$3,623(97)	$1,314	$4,938(92)	$456	$166	$622
With gap	12	83.3	189.4	$7,141(86)	$8,232	$15,373(81)	$86	$99	$184
Post-lt 210	108	87.4	266.4	$7,056(81)	$7,812	$14,869(56)	$762	$844	$1,606
Post 210+	25	210.0	374.6	$21,108(101)	$1,022	$22,131(59)	$528	$26	$553
Total	1,522	35.8	53.4	$3,495(98)	$ 989	$4,484(84)	$5,320	$1,505	$6,825
Home Health Based									
TotHosp	12,311	28.3	28.3	$2,436(86)	$396	$2,832(100)	$29,990	$4,875	$34,865
No Cap	3,547	44.4	57.3	$3,334(75)	$1,585	$4,920(86)	$11,826	$5,622	$17,448
With gap	331	94.6	190.7	$6,961(74)	$5,044	$12,006(63)	$2,304	$1,670	$3,974
Post-lt 210	2,493	90.8	275.2	$7,245(80)	$5,393	$12,639(46)	$18,062	$13,445	$31,507
Post 210+	278	210.3	410.4	$20,030(95)	$3,252	$23,282(57)	$5,568	$904	$6,472
Total	18,960	43.4	74.6	$3,573(82)	$1,398	$4,972(67)	$67,750	$26,516	$94,265
Freestanding Based									
TotHosp	13,916	31.3	31.3	$2,353(75)	$361	$2,714(87)	$32,744	$5,024	$37,768
No Cap	2,892	52.7	69.1	$3,735(71)	$1,402	$5,137(74)	$10,802	$4,055	$14,856
With gap	327	87.7	180.8	$6,042(69)	$4,803	$10,845(60)	$1,976	$1,571	$3,546
Post-lt 210	2,640	92.4	271.8	$7,349(80)	$5,388	$12,737(47)	$19,401	$14,224	$33,626
Post 210+	492	210.0	421.5	$20,199(96)	$2,251	$22,451(53)	$9,938	$1,107	$11,045
Total	20,267	47.6	79.9	$3,694(78)	$1,282	$4,976(62)	$74,861	$25,981	$100,842
Total									
TotHosp	31,655	29.9	29.9	$2,439(81)	$370	$2,809(94)	$77,207	$11,699	$88,906
No Cap	7,752	47.0	61.7	$3,454(74)	$1,455	$4,910(80)	$26,778	$11,278	$38,056
With gap	783	90.8	193.9	$6,396(70)	$4,931	$11,328(58)	$5,008	$3,861	$8,870
Post-lt 210	6,096	92.3	279.8	$7,259(79)	$5,334	$12,593(45)	$44,252	$32,515	$76,767
Post 210+	885	210.1	415.1	$19,964(95)	$2,618	$22,582(54)	$17,668	$2,317	$19,985
Total	47,171	45.2	77.4	$3,623(80)	$1,307	$4,931(64)	$170,914	$61,670	$232,584

Figure 3-1


Medicare Hospice Enrollment:
Est. Percent of Cancer Deaths
30.0%
25.0%
20.0%
15.0%
10.0%
5.0%
0.0%
1.7%
4.6%
6.9%
9.3%
15.4%
20.0%
23.4%
1984
1985
1986
1987
1988
1989
1990
% of Cancer Deaths
Sources: HCFA Enrollment
NCHS: Mortality

CHAPTER 4

CLINICAL ADVISORY PANEL

4.1 Purpose

The third source of information for this report was expert input from a CAP. The purpose of assembling the clinical experts was to gather information on the relative prevalence, feasibility of use, and costs of a variety of pain control interventions, focusing on those interventions considered to be high cost. Nine experts in pain control and hospice care met for 2 days (December 13 and 14, 1990) with Project HOPE and HCFA staff to discuss these and other issues related to the provision of these interventions in hospices and other settings.

The assembled panel included leading experts in fields relevant to the provision of palliative care to hospice patients. Specifically, the panel included an oncologist, a pharmacist, an ethicist and hospice medical director, a neurologist, a clinical nurse, an AIDS expert, an anesthesiologist, and representatives from both the NHO and the Hospice Association of America. The names and affiliations of the panel participants are presented in Appendix C, as is a comprehensive summary of the CAP deliberations. This chapter summarizes the major discussion points of the meeting. The discussions are categorized into five broad areas: 1) defining the high cost problem; 2) general considerations; 3) identifying high cost interventions; 4) suggested reimbursement mechanisms; and 5) proposed research agenda.

4.2 Defining the High Cost Problem

Throughout the panel deliberations, the discussion suggested that while Medicare's recently increased basic payment rate is generally considered adequate, there exists a set of high cost interventions or procedures provided to a few patients which, in the short run, may result in substantial financial risk to a hospice provider. However, because little is known about which interventions are high cost, and which of these are used frequently in hospice settings, the nature and extent of this problem remains unclear.

Initially, the panel defined the nature of the high cost problem as an access issue. Two populations were identified as having reduced access to hospice care because of the potentially high costs of providing their care: 1) the indigent or homeless who are unlikely to receive hospice care because they lack a primary caregiver at home or live in a situation that is unsuitable for the provision of home based hospice care; and 2) potential hospice patients that are diverted directly or redirected away from the hospice system because they are likely to need either extensive inpatient care or expensive forms of treatment.

Although access to hospice care by these populations was considered a major concern. panelists were asked to focus their discussion on the high cost interventions provided to patients who are already in the hospice system that may present financial risks to hospice providers. While the high cost problem was not explicitly defined, panelists agreed that many hospices are struggling with the costs of providing newer, sometimes more technologically sophisticated and sometimes more expensive medications and other types of interventions. Panelists were aware of the short term need to concentrate on the theoretically relatively small number of "outlier" patients already in the hospice system who require more expensive forms of care, rather than on the larger issue of patients who lack access to hospice care. The remaining discussion concentrated on the high cost problem posed by these newer interventions and on suggested changes to the current reimbursement structure.

4.3 General Considerations

The panelists felt that several points reiterated throughout both days' deliberations should be highlighted as a set of general considerations providing a context within which their list of high cost interventions and suggested reimbursement mechanisms should be reviewed. These considerations are as follows:

- Reimbursement system modifications, in the short run, should focus on accommodating circumstances under which symptom palliation is provided by a high cost intervention (after less costly alternatives have been found inadequate).

- The patient and hospice provider should have control over making decisions about whether or not particular interventions are medically appropriate.

- There must be medical guidelines or standards in place in order to provide some check against misuse or abuse of the identified interventions once reimbursement is available. A utilization review mechanism would provide an additional check for misuse and/or abuse.

- Evaluation of the impact of modifications to the reimbursement structure should be undertaken.

- More research is needed on which types of interventions or groups of interventions are costly and how frequently they are used (lack of appropriate baseline research hinders the ability to identify specific high cost interventions).

4.4 Identifying High Cost Interventions

Early in the discussion, the panelists indicated that they could only provide anecdotal cost and use information for specific interventions. While recognizing that hospices are facing financial difficulty by providing some of the newer palliative interventions, there is little more than anecdotal evidence to support these claims. They noted that it is very difficult to gather cost data, and of the data that currently exist, few are specific to the hospice setting. However, the panelists felt that they could develop a list detailing the types of interventions that could lead to potentially extreme financial liability for most hospices.

An initial discussion of high cost interventions involved identifying patient characteristics that might be indicators for patients likely to need expensive treatments. This implies that patients requiring high cost interventions can be identified at admission, or at least very early in their use of care. Two examples were a diagnosis of AIDS and those presenting with difficult-to-manage pain. However, after some discussion, both of these were rejected as characteristics identifying high cost patients. For example, other patients may present with similar treatment needs as AIDS patients but without a diagnosis of AIDS. These patients therefore will not be identified as a potentially high cost patient. In addition, several panelists stated that difficult-to-manage pain can develop at any point in a patient's illness, and this potential development is not necessarily discernible at the point of admission. While the question of whether high cost indicators exist was not definitively answered, enough caveats to the examples were presented that the issue was not revisited.

Discussion of a list of procedures and interventions considered to be high cost was initiated by one panel member's suggested list. After much debate, the panelists developed a final list of interventions that they felt included the range of high cost interventions provided to hospice patients. This list provides identification of types of medications, modes of administration, and types of procedures that can lead to high costs:

- IV administrations for pain medications, antibiotics, transfusions, hydration, chemotherapy, and TPN;
- medication delivery systems that require intraspinal and continuous subcutaneous access;
- palliative radiation therapy;
- surgeries related to the terminal illness; and

- drugs that cost more than some threshold percentage above the average total cost of drugs normally used in palliation of symptoms for terminally ill patients.

Total costs for drug therapy, when relevant for a contracted service (e.g., for infusions) refers to cost of supplies, equipment, and drugs, and may include labor. Further work needs to be done to identify the appropriate drug cost threshold, particularly before a reimbursement policy for medications could be appropriately structured.

During the development of this list, several concerns were raised about providing additional reimbursement for these interventions. First, panelists preferred to avoid listing specific medications so that the list would encompass medications currently under development or likely to be developed in the future. One allegation made about why the current reimbursement amounts were inadequate for covering the costs associated with state-of-the-art interventions was that these newer technologies were not generally available in the home care setting at the time the hospice legislation was drafted. While the newer technologies might seem more expensive because of higher initial costs, they may also be more efficient or appropriate overall and, thus, reimbursement should be made available. Panelists therefore preferred to ensure that future developments would be considered eligible for reimbursement. In addition, panelists noted that high cost interventions are not always only those that are high tech. This list, by including modes of administration and cost thresholds, is intended to cover high cost interventions, regardless of technological sophistication.

Second, there was also concern about the incentives inherent in providing additional reimbursement that might lead to overuse, or inappropriate use, of a newly-covered intervention. In particular, panelists were concerned that the existence of reimbursement might replace the already difficult discussion with the terminal patient and their families about the clinical rationale for providing an intervention. It was in this context that panelists discussed the issue of reimbursement based on appropriate use as stipulated in a set of guidelines or standards specific to terminal care in hospice settings. However, panelists also acknowledged the difficulty in establishing hospice-specific guidelines given the absence of hospice based research on the effectiveness and use of various palliative interventions. In addition, not all hospice providers are convinced that providing the newer, sometimes more sophisticated and sometimes more expensive interventions is necessary for the provision of hospice services. Guidelines for the use of interventions that some hospices have a philosophical bias against would be controversial.

Third, there was extensive discussion about providing exclusions for surgery and radiation therapy. Surgical procedures were considered easy to identify as producing cost outliers, viewed as less discretionary than other types of procedures, and seen as a distinct end of the treatment continuum. There was some discussion about whether

radiation therapy should be treated in a fashion similar to surgery, but there was concern expressed that, given additional reimbursement, there is more likely to be inappropriate increases in the use of radiation therapy than in surgery. It was unclear whether radiation therapy is always an expensive intervention (one panelist cited an approximate cost of $1 per rad as a ballpark figure, and a typical course of therapy including the treatment plan might cost $3,000). Although the discussion was inconclusive, palliative radiation therapy remained on the list as a probable high cost intervention.

Finally, there was a set of issues relevant to locus of decisionmaking control over choosing specific interventions. All panel members felt strongly that the patient, patient's family, and the hospice provider should maintain control over the course of treatment. Some panelists were concerned that inadequate reimbursement for some of these interventions were forcing hospice providers to obtain treatment through other sources, thus losing some continuity of treatment for the patient.

4.5 Suggested Reimbursement Mechanisms

Due to the focus on high cost interventions, panel members felt that short-term modifications to the current reimbursement structure should allow hospices the flexibility to provide clinically appropriate, state-of-the-art interventions without becoming concerned about the potential financial liability (and thus perhaps refusing to provide these treatments for financial reasons). The panel made several suggestions for reimbursement mechanisms. These suggestions were intended to allow reimbursement for high cost interventions, and, in conjunction with use guidelines, discourage inappropriate use. The suggested mechanisms included:

- an exceptions/exclusion process for specific interventions;
- a risk pool available to hospices for reimbursing high cost cases;
- a cap on the number of outliers (for which additional reimbursement would be provided);
- a decreasing partial reimbursement scale for dollar amounts over a specified amount;
- a fifth reimbursement category; and
- a general rate increase.

Discussion of some of the advantages and disadvantages of these suggestions are provided in the full summary in Appendix C.

4.6 Proposed Research Agenda

In addition, the panelists specified a research agenda. They felt particularly strong about the lack of data on the costs and use of interventions that are considered to be high cost. Other areas of research priority they identified include:

- identifying the costs of treatment in a hospice compared to costs for treatment of individuals left out of the system (one panelist emphasized the need for precise definition of costs);
- identifying the proportion of patients who elect out of the hospice benefit to receive high cost treatments;
- finding the number of patients denied hospice care because they are likely to require high cost care;
- supporting a comprehensive study of drug costs to help specifically identify high cost medications; and
- developing research into whether incorporating homeless individuals or those without a primary caregiver would reduce the costs of their care by substituting for acute hospitalization (and to what degree doing so would benefit them).

In general, the panelists recognized the existence of a relatively small set of types of interventions leading to potentially extreme financial liability for hospice providers. Also apparent, however, are the difficulties in modifying the current reimbursement given the absence of data with which to understand the scope and nature of the problem and the type of modifications that would ease the supposed cost burden for hospices. Evidently, more knowledge of specific interventions and the frequency and costs of these interventions is needed.

CHAPTER 5

HIGH COST INTERVENTION STUDY

5.1 Purpose

In order to develop possible modifications to the current system for hospice reimbursement, HCFA first needs better information on the specific services provided to Medicare beneficiaries and which of these services are high cost. Because Medicare pays hospices on a per diem basis and not per procedure or intervention, Medicare records do not specifically identify the procedures or interventions provided by hospices.

To supplement the existing data, the NHO designed and conducted a provider survey that would identify high cost hospice interventions. At the very least, the NHO survey was constructed to provide more detailed information about which hospice patients and/or interventions are high cost. Additional information the survey was designed to obtain was:

- use of these high cost interventions at the hospice and beneficiary level;
- characteristics of the beneficiaries receiving these interventions;
- how these interventions are associated with beneficiary clinical measures such as pain level and functional status.

This survey represents the first research effort aimed at identifying the costs and use of specific interventions provided to Medicare beneficiaries in hospices. The NHO designed and fielded the survey, and Project HOPE developed a data base from the survey responses and subsequently analyzed the data. This section describes the survey development, methodology, analysis, and results of this effort.

5.2 Sample Selection Process

Selection of a sample of hospices from which to obtain information on high cost hospice care proceeded in two phases. First, the NHO conducts an annual survey to track facility and patient characteristics of all hospice and palliative care facilities that they know are in existence in the United States. In 1990, as shown in Table 1, 1,766 hospices responded to this survey. This survey is designed to collect basic information about hospice programs in the United States. An additional question was added to the 1990 Survey Report Form asking whether any of nine specific interventions were provided as part of the hospice scope of care. The intervention list was developed by NHO in consultation with HCFA, based on anecdotal evidence on which services are

considered to be high cost. These interventions are: 1) palliative chemotherapy, 2) palliative radiation, 3) antibiotic use, 4) morphine pump use, 5) AZT, 6) TPN, 7) surgery, 8) erythropoietin (EPO), and 9) dialysis.

As shown in Table 5-1, over half of the hospices responding to the first survey, 55.1 percent, provided at least one of these interventions, and three-fourths of the Medicare-certified hospices responding to the survey reported that they provided at least one of these interventions. The set of all Medicare-certified hospices that responded "yes" to providing at least one of the nine interventions (653 hospices) provided the sampling frame for a second survey on high cost interventions. Thus, the hospices selected into the final sample were the Medicare-certified hospices that provided at least one of the nine interventions initially identified as potentially high cost (508 hospice facilities).

Second, a supplemental survey, the High Cost Interventions Study (HCIS), was sent to all of the 508 hospices in the sample in June 1990. This survey asked the hospices for more specific information about high cost interventions and also about characteristics of the patients receiving any type of hospice-identified high cost intervention. The sample of hospices, therefore, includes all the Medicare-certified hospices responding to the annual membership survey who also responded "yes" to providing at least one of the nine high cost interventions as part of their scope of care. Eighty-eight hospices responded to the HCIS survey. The use of some interventions (specifically antibiotics, morphine pumps, chemotherapy, and radiation) by Medicare-certified hospices is much greater than use of these interventions by all hospices. According to these data, antibiotics and morphine are the most commonly provided of the nine high cost interventions, while dialysis and EPO are not provided very often.

5.3 Survey Design and Methodology

The NHO'S High Cost Interventions Study (HCIS) initially was designed to gather basic information on interventions identified as being high cost and on the patients receiving these interventions. Each hospice receiving the HCIS survey was asked to identify all of the patients in their program who the hospice considered to be high cost and provide detailed information on the interventions provided to these patients. Information requested includes the type of intervention, the unit of measure for that intervention (e.g., visits), the frequency of occurrence of the unit of measure (e.g., the number of interventions), and the total cost of that intervention.

For much of this information, hospice providers had to obtain information from each patient's medical record. Providers responding to the survey were permitted to identify up to six interventions per patient. These interventions were those that the hospice itself considered to be high cost. Clinical and sociodemographic information (age, sex, race, diagnosis, functional status, pain level, and health benefit status) and length of stay

information was also collected. Functional status, pain level, and health benefits status were identified at three points in time: 1) at admission; 2) during the interval when interventions were provided; and 3) at discharge. A copy of the survey form is included in Appendix D.

5.4 Limitations of the Survey Design and Methodology

Although the HCIS was formulated to gather a large amount of detail about hospice patients and interventions considered to be high cost, there are several limitations to the survey methodology and design that have implications for Project HOPE's analysis of the data.

First, there are two potential sources of bias in the sampling process. One source of bias is potential response bias for hospices responding to the first survey (the 1990 NHO's annual survey). Hospices responding to this survey may be more likely to be larger facilities and NHO members. Therefore, there may be some number of smaller facilities not identified for this survey. However, these smaller facilities are also less likely to be Medicare-certified and less likely to provide the newer, more sophisticated pain control technologies on a regular basis.

The second source of bias is the sampling frame for HCIS. According to NHO sources, anecdotal information from several hospices identified a wide range of interventions beyond the nine listed on the first survey that could be considered high cost. The second survey was changed to allow hospice providers to self-define the high cost interventions that they provided, rather than focus on the initial nine interventions listed on the first survey. Thus, instead of requesting information on the nine previously identified interventions, each hospice responded with information on any interventions provided to the patients that the individual hospice considered to be high cost.

This framework poses two problems. First, only Medicare-certified hospices responding "yes" to the provision of any one of the nine interventions identified on the first survey were sent the second survey form. Hospices that responded "no" to providing all of these nine interventions were not included in the sample for the second survey. However, these hospices may provide other interventions that are high cost and, under the expanded definition of high cost care in the second survey, should be included in the study. In effect, information about these other potentially high cost interventions is potentially underreported from the data set. Therefore, hospices providing high cost services that were not identified on the first survey may have been screened out of the potential sample prematurely (88 out of 756 Medicare-certified hospices responded; see Table 2 and related discussion on representativeness of the sample). In addition, the first survey did not explicitly distinguish between programs providing these interventions on a regular basis from programs providing these interventions on an irregular basis.

The second problem lies with the lack of clarity in defining a high cost patient or intervention. Because hospices were free to develop their own parameters for identifying high cost cases or interventions, the survey yielded a large variety of interventions and inconsistent reporting of information associated with the provision of these interventions. The survey instrument also lacks specific instructions on how to measure other variables. As a result, hospices may not be responding in a completely uniform manner. This may seriously impinge on the usefulness and the generalizability of the data. Two examples of the survey design problems are mentioned below to illustrate how they affect the data analysis.

The survey asked hospices to identify patient functional, pain and payment status at three different points in time: 1) at admission; 2) during the interval when the interventions were provided; and 3) at discharge or death. However, hospices were not asked to define these points in time, or phases, more specifically and therefore may have had different interpretations of these time intervals. Because the definition of time intervals is not known to be consistent, the measures of pain and functional status around these points in time are subject to measurement error. For instance, it is not known whether pain status refers to the pain that led to the intervention or the pain that followed the intervention.

Perhaps the issue most relevant for HCFA in analyzing the results of the survey pertains to how high cost interventions are defined and measured. No guidelines were given to hospices on how to identify a high cost patient or define a high cost intervention. In many cases, it can not be determined whether the intervention includes only the specific intervention (e.g., morphine pump), or instead, refers to the total service provision (e.g., associated labor, nursing visits, pump implantation, etc.). In addition, only a broadly inclusive definition of costs is provided. Total costs were defined in the survey as "the sum of all expenses associated with a specific intervention during the patient's stay in the hospice program." Again, it is unclear whether hospice providers interpreted this to mean only the specific intervention or the total service provision related to the intervention. Therefore, the reliability and validity of the utilization and cost data is limited.

For example, a patient may have been high cost in terms of total expenditures due to a very long hospice stay. However, if the per diem payment levels fully covered the costs of treatment, then the patient was not high cost at all. In terms of the Congressional mandate, the definition of high cost is relative to the payment rate. That distinction was not made clear to the hospice participating in the survey.

Despite these survey design problems, a data analysis plan was developed with the aim of using survey information to provide some insight into which interventions hospices consider to be high cost, and which patients are receiving these interventions. While the data cannot be considered as representative of either hospices, patients, or

interventions, the analysis does provide preliminary information about interventions provided in hospice settings that hospices consider to be high cost and thus may lead to extreme financial liability for a hospice provider. It is important to remember throughout the discussion of the analytic results that references made to high cost patients or interventions relate to the patients or interventions identified by responding hospices as high cost, not to a predefined notion of what constitutes a high cost patient or service.

5.5 Analytic File Construction

Several steps had to be undertaken before the data could be analyzed. Due to the survey instrument design, creating the data base and coding the information was complex and difficult. Lack of explicit definitions led to data that are qualitative in nature, making it difficult to define specific variables and ranges of variable response. The first step involved determining which survey questions yielded responses that were useful. Data fields were created for each of these questions (Appendix F includes the complete list of data fields.) The second step involved reviewing the range of answers for each of these questions and determining a coding guide for these responses.

The interventions were the most complicated responses to code. Project HOPE staff conducted a detailed review of 10 surveys to develop a coding guide that listed the more commonly occurring interventions and assigned each of them a number (see Appendix F). The survey review also showed that some of the hospices defined an intervention more precisely than others. For example, some hospices reported more generally on the use of narcotics while others specifically named the narcotic used. The coding guide accounted for this by defining interventions both under a general category (Type of Intervention) and under a more precise category (Specific Intervention). The coding sheet also defined the more commonly mentioned units of measure, dosage measure, and route of administration for the interventions. Each of the responses to these items also was assigned a number so that data entry and analysis could be performed more easily.

Because a great deal of the survey involved qualitative clinical responses that are not easily interpreted by nonclinicians, all the initial coding was done by nurses. These nurses were trained to code survey responses onto a coding form using the developed coding guide. The nurses' work was reviewed by Project HOPE staff to ensure coding consistency. After the initial coding was complete, the information was reviewed to see if some responses could be coded more precisely. For example, additional medication fields were added because multiple medication use was frequently observed. After these changes were made, the data were keyed into a data base format.

In order to ensure that all information entered into the data base was keyed in accurately, the intervention information keyed into the data base for every fifth intervention was reviewed against the information on the coding forms.

Despite these accuracy checks, the use of some of the data fields should be interpreted with care. Particular intervention-level fields (i.e., cost, unit of measure, route of administration and frequency--per case) are subject to certain caveats.

Frequency distributions of costs for each specific intervention revealed that the interpretation of total costs associated with the reported interventions varied widely across providers. The cost information was deemed misleading and not used in the analysis.

For particular interventions, such as radiation therapy, narcotics, chemotherapy, general medications, hydration blood therapy and antibiotic therapy, numerous inconsistencies in reporting unit of measure existed. While for some interventions the reported units of measure could be converted into comparable measures, for other interventions (e.g., chemotherapy and radiation therapy) comparable measures could not be developed. As a result, the usefulness of these data is limited.

The unit of measure for most medications also was inconsistently reported. Hospices reported the unit of measure for medications in one or more of the following ways: 1) by reporting the number of days the medication was given; 2) by defining the dose that was given; or 3) by referring to the unit of measure more generally (i.e., "x" quantity of tablets, "x" quantity of bottles). Ideally, all of these unit of measure variables should have been reported for each medication intervention to make frequency comparisons of the medication interventions more accurate.

In order to code the medication information as precisely as possible, Project HOPE created other unit of measure fields to reflect each of these responses. Additional fields were used to record the dosage, the frequency of dosage, and the frequency of days information whenever they were reported. The creation of these fields helped to ensure that all of the frequency data were coded. However, for particular interventions, the small number of times that complete information was recorded limits the analysis of these variables.

Certain assumptions were also made in coding the route of administration information. Medications that were continuously administered were not always identified on the surveys as specifically as possible. For these cases, the route of administration was coded as intravenous continuous, the least specific of all of the continuous administration categories. For many of the PCA interventions, the exact route of administration category was not specified. These interventions were therefore assigned to another general route of administration category, subcutaneous infusion.

Because the above-mentioned caveats related to some of the primary data fields, Project HOPE limited the analysis to the more clearly coded and somewhat more consistently reported data fields. Accessory qualitative information about the cost, dose, route of administration and the unit of measure for interventions were eliminated from the analyses. Therefore, the results focus on variables that are somewhat less subject to interpretation and reporting error. These variables include diagnosis, pain level, functional status, length of stay, payment status, type of intervention, specific intervention, and the number of cases receiving an intervention.

5.6 Results: Hospice and Patient-Level Analyses

Out of the 508 Medicare-certified hospices who were sent the HCIS survey, 88 (17.3 percent) responded. The first analyses conducted with these data were a brief exploration of hospice facility characteristics (organizational base, facility size, and geographic distribution) and of the proportion of total patient caseload that hospices reported as being high cost. These analyses involved two steps: 1) examining facility characteristics from the first survey (the NHO annual survey); and 2) linking the total number of patients admitted (from the NHO annual survey) to the number of patients identified by each hospice as being high cost cases (reported on the HCIS survey).

Of the 88 hospices responding to the HCIS survey, information about the organizational base of the hospices was available for 84 facilities. As shown in Table 5-2, over half of these 84 (60 percent) are independent facilities (community based programs limited to care of terminally ill persons). The next largest category is hospital based hospices. Nineteen hospices in the HCIS sample are hospital based (23 percent). Twelve hospices are home health agency based programs (14 percent), one is part of a coalition of health care facilities, and none are nursing home based. Comparing these data to recent HCFA data (also on Table 5-2) shows that the hospices responding to the HCIS survey are not generally representative of the universe of Medicare-certified hospices. The HCIS sample of hospices underrepresents home health agency based hospices and overrepresents independent facilities.

Tables 5-3 and 5-4 examine hospice facility size of the respondent hospices as represented by the total number of patients admitted and the number of Medicare beneficiaries admitted in 1989. As shown in Table 5-3, just over one-third (38.6 percent) of hospices admitted between 100 and 199 patients in 1989. Over one-fifth (21.7 percent) admitted between 50 and 99 patients, and another 21.7 percent admitted between 200 and 499 patients in 1989. There are five large facilities (over 500 patients) and 10 smaller facilities in the sample.

Examining Table 5-4, the distribution shifts down and the highest proportion of hospices (31.3 percent) reported admitting between 50 and 99 Medicare beneficiaries in 1989. Twelve percent of hospices reported admitting between 25 and 49 Medicare

beneficiaries and 23 percent admitted between 100 and 199 Medicare beneficiaries. Compared to Medicare data on the number of Medicare beneficiaries served in 1987, the hospices in the HCIS sample appear to be those that serve between 50 and 200 Medicare beneficiaries. Hospices that serve fewer Medicare beneficiaries and those serving over 500 Medicare beneficiaries appear to be underrepresented by the HCIS sample.

Table 5-5 shows the geographic distribution of hospices responding to the HCIS survey and the proportion of total hospice caseload reported as being high cost. The geographic distribution of Medicare-certified hospices, according to HCFA data, is presented in the last column for comparison purposes. The 82 hospices for which these computations were possible represent approximately 11 percent (10.8 percent) of all Medicare-certified hospice facilities.

In order to assess what proportion of these hospice's total caseload was considered, by the hospice, to be high cost, the number of patients identified as high cost by each hospice as a proportion of total patients admitted was computed. The data in Table 5-5 show how many Medicare-certified facilities considered that less than 10 percent, 10-14 percent, 15-19 percent, 20-24 percent, or over 25 percent of all their patients were high cost. High cost cases comprise less than 10 percent of the total case load for over half of the hospices responding to the HCIS survey (53.7 percent), while approximately 13 percent of the facilities identified over 25 percent of their caseload as high cost. Thus, the overall cost impact for these facilities may not be evenly distributed. Facilities having a much greater proportion of high cost cases may be at greater risk for financial problems.

Almost half of the hospices (46.3 percent) identified over 10 percent of their total case load as high cost. This appears to be a surprisingly large proportion of total hospice patient case load that is identified as high cost. However, this table indicates that the responding hospices have not identified the few patients that represent true outliers in terms of costs, but have identified a much broader sample of patients. Lack of a clearly defined notion of what type of patient or intervention should be considered as high cost for this particular survey resulted in widely varying definitions of high cost patients and/or high cost care, and, thus, variations in the proportion of total case load that is identified as high cost.

Demographic Characteristics and Source of Payment

The next series of analyses focused on patient-level characteristics for patients identified as high cost. Data on 1,681 cases identified as high cost were provided by hospices responding to the HCIS survey. Although hospice patient mix may change as the hospice industry continues to grow (e.g., more AIDS patients or patients with terminal conditions other than cancer may utilize hospice care), hospice patients traditionally

have been predominantly white, elderly patients with terminal cancer. HCIS data on the high cost hospice patients identified by providers indicate that their demographic profile does not appear to be distinctly different from patients who are not identified as high cost.

As shown in Table 5-6, slightly more than half of all patients identified as high cost are male (53.2 percent), and the majority of these patients are white (89.6 percent) and over age 65 (64.1 percent). This is also true for both the 974 Medicare hospice and the 100 Medicare home health beneficiaries[1] identified as high cost (although female beneficiaries account for just over one-half of the Medicare home health patients).

Comparison of the specific age categories for all patients with those of Medicare beneficiaries, however, reveals that a much higher proportion of Medicare hospice and home health beneficiaries are over age 65 (89.8 and 83 percent, respectively). Given that many Medicare beneficiaries electing the hospice benefit are more likely to be Medicare eligible because of old age than because of other eligibility criteria (e.g., disability or ESRD), this finding is reasonable.

These data are consistent with those on all hospice patients and Medicare hospice beneficiaries obtained from other sources, thus, demographic characteristics do not seem to distinguish high cost cases from other cases. Early hospice program data indicate that just over half of the Medicare beneficiaries in hospices in 1984 and 1985 were male and the majority were white (Davis, 1988). While it would be informative to examine further the age distribution of the high cost patients above age 65, the structure of the age question on the HCIS survey instrument prevents this analysis.

The age and ethnic distributions of Medicaid and All Other hospice patients identified as high cost reveal slightly different patterns than observed for the Medicare beneficiaries identified as high cost. The majority of Medicaid recipients identified as high cost are between the ages of 20 and 64, with the largest proportion (43.4 percent) in the 35-49 age category. Compared to patients in other payment categories, a higher proportion of Medicaid patients are black (13.3 percent) or hispanic (9.6 percent). For All Other patients, the largest proportion are in the 50-64 age category (47.9 percent), but again the majority of these patients are white (89.6 percent).

In the HCIS survey, hospice providers were asked to identify the source of payment for each patient at three points in time: 1) at admission; 2) during the interval when interventions were provided; and 3) at discharge. Table 5-7 summarizes these responses. The distribution of payment source is similar regardless of the point in time

[1] Home health beneficiaries hereafter refers to beneficiaries who have not elected the hospice benefit, but use regular Medicare Part A and Part B covered services.

when the assessment of payment source was made. Over 80 percent of hospice patients identified as high cost are either covered by Medicare hospice or private health insurance. The similarity of the payment source distributions across different points in time indicates that there is little shift between payment sources during these patients' stays in a hospice program.

Length of Stay Patterns

The average length of stay in a hospice program, for Medicare hospice patients identified as high cost, was approximately 88 days (see Table 5-8). This is almost twice as high as the average length of stay typically reported overall for Medicare beneficiaries in hospice care. In 1984 and 1985, the average length of stay for Medicare beneficiaries was 29.3 and 32.1 days, respectively (Davis, 1988). By the last quarter of 1988, average length of stay increased to 46.6 days, and by the second quarter of 1989 average length of stay reached 47.9 days (HCFA, 1991).

Examining the distribution of patient length of stay across several length of stay intervals also reveals some interesting patterns. From Table 5-8 it can be calculated that approximately half (478 cases, 48.5 percent) of the Medicare hospice beneficiaries identified as high cost had lengths of stay of over 60 days, while one-third had stays of approximately 1 month. Approximately one-eighth of these high cost Medicare hospice cases (118 patients, 25 percent of those with stays over 61 days) have lengths of stay exceeding 210 days. Although the median length of stay indicates that the length of stay distributions are somewhat skewed, the median is still higher than the average length of stay typically reported for Medicare hospice beneficiaries, indicating that the patients in the HCIS sample have distinctly longer lengths of stay.

Sixty percent of Medicaid hospice patients identified as high cost also had lengths of stay of over 61 days (35 cases). Over one-third (34.4 percent) of Medicaid home health patients had lengths of stay of over 180 days. The Medicaid hospice and home health patients had longer average lengths of stay than any other payer category, 110 and 147 days, respectively, as well as higher median lengths of stay.

These patterns indicate that patients identified as high cost are those that have unusually long lengths of stay. While these patients may be high cost in terms of overall expenditures, due to long stays, they do not necessarily have high per diem costs. These patients may have exhausted their benefit coverage and the hospice is then forced to continue providing services without reimbursement.

For patients covered by private health insurance, 61 percent had stays of 60 days or less, unlike the Medicare and Medicaid hospice patients. Approximately 40 percent of private insurance patients had stays of no more than 1 month. Exactly half of both the self-pay and indigent patients had lengths of stay of less than 60 days. Thus, while

Medicare and Medicaid hospice patients appear to experience a longer length of stay, patients identified as high cost who are covered by private health insurance appear to have shorter lengths of stay patterns.

Despite our focus on high cost interventions as the factors driving the high costs associated with certain hospice patients, the hospices in the HCIS sample seem to have identified the patients who have large absolute costs because of longer lengths of stay. In conjunction with the data in Table 5-5 showing the proportion of total case load that is identified as high cost, it appears that hospices have not provided information for the patients who represent cost outliers, but for a broader sample of patients.

This is consistent with Medicare hospice data on length of stay and expenditures. Medicare data indicate that the median survival time for Medicare hospice patients is approximately 1 month and that approximately 80 percent have died by 3 months of their hospice stay. In addition, those that live longer than 91 days are likely to incur a disproportionate share of hospice expenditures. However, this is due to long life not because they have high per diem costs (HCFA, 1991).

In addition, assuming that pain as a symptom of cancer typically intensifies over the course of disease, the patients who live longer (or who may have entered hospice at an earlier stage of disease) may require more intense treatments for pain. For example, as the disease progresses and increased oral narcotic use may no longer provide effective pain relief, more sophisticated delivery systems may be useful. These more sophisticated delivery systems are the interventions frequently cited as being associated with high costs. However, while use of high cost interventions may at least contribute to higher absolute costs for these patients, not all of these patients are necessarily receiving the higher cost interventions.

Functional Status and Pain Level

Tables 5-9 and 5-10 present data on hospice patient functional status and pain level over time spent in the hospice program. Hospice providers were asked to assess functional status and pain level at three points in time: 1) at admission; 2) during the interval when interventions were performed; and 3) at discharge. Table 5-9 follows changes in patient functional status over time by controlling for functional status at admission.

Functional status was measured as one of three categories, whether the patient was ambulatory, intermittent ambulatory, or nonambulatory at the point of assessment. Most patients experienced a decline in functional status over time. For patients who were ambulatory at admission (n=717), over half were intermittent ambulatory during the interval when interventions were provided (57 percent), and over three-quarters were nonambulatory at discharge (80.4 percent).

During the interval when interventions were provided, over half of the patients who were intermittent ambulatory at admission (n=501) remained intermittent ambulatory; however, a small number (1 percent) were ambulatory and over one-third (37.7 percent) had moved into the nonambulatory category. By time of discharge, the majority were nonambulatory (88.1 percent). While the majority of patients who were nonambulatory at admission (n=356) remained nonambulatory at the other assessment points, a small number experienced some improvement in functional status.

The average and median length of stay for patients with different levels of functional status at admission also was calculated. The average length of stay for patients who were nonambulatory at admission was the lowest, 57 days, and for patients who were ambulatory at admission it was the highest, 113 days. The median lengths of stay are 79, 43, and 20 days, respectively, for patients who were ambulatory, intermittent ambulatory, and nonambulatory at admission. These results are not surprising if the assumption is made that patients at a more advanced stage of disease (and thus likely to have shorter lengths of stay) are less likely to be ambulatory at admission.

In summary, then, this table reveals that functional status deteriorates for most of the patients identified as high cost over the progression of their disease. Only a few patients experience improvements in functional status. In general, most of the interventions identified by the hospice providers for this survey are not targeted toward improving functional status but, rather, toward relieving pain. In fact, some of these interventions could affect patient neurological status such that mobility is impaired, a more likely cause of functional deterioration than the disease progression itself. In addition, these data do not include information about other interventions that may have been used but were not considered by the hospice to be high cost interventions. To assess adequately the impact of the identified interventions on changes in functional status, much more information would be required.

Table 5-10 examines changes in pain level across the three time periods controlling for pain level at admission. Almost one-third (31.7 percent) experienced mild-moderate pain during the interval when interventions were performed, and just under one-fourth (24.6 percent) experienced mild-moderate pain at discharge.

This table indicates that some patients did experience improved pain relief over their hospice stay. Examining data for patients who entered the hospice experiencing mild-moderate pain (n=816), some interesting patterns emerge. Over half of these patients still experienced mild-moderate pain during the interval when interventions were provided, but over one-third shifted into experiencing either no pain (12 percent) or strong-severe pain (29.9 percent) at the same point in time. Thus, while pain intensified for 244 patients, 98 patients experienced improved pain control. At discharge, 42 percent remained in the mild-moderate pain category, while over 36

(n=315) percent experienced improved pain control and moved into the no pain category. Slightly fewer patients were experiencing strong-severe pain at this point than during the interval when interventions were provided.

Improved pain control is also revealed for some patients entering a hospice program with strong-severe pain. During the interval when interventions were performed, approximately 42 percent of these patients moved into less severe pain categories (10.4 percent were observed as experiencing no pain, and 32.9 percent were experiencing mild-moderate pain at this time). By discharge, almost 60 percent had moved into less severe pain categories (35.1 percent were experiencing no pain and 24.9 percent were experiencing mild-moderate pain). A few patients also moved into the more severe category of pain. Eighteen patients were experiencing intractable pain when interventions were provided (5 percent), and 14 patients were experiencing intractable pain at discharge. Lastly, for patients who entered hospice programs experiencing intractable pain, over half moved into less severe pain categories during their hospice stay.

Average and median length of stay was also calculated for patients with different pain levels at admission. Average length of stay decreases for patients entering the hospice with higher intensity pain, ranging from approximately 94 days for patients entering with no pain to 65 days for patients entering with intractable pain. The median for all pain level groups is similar and ranges from 52 to 55 days.

Similar to the length of stay results for patients with different levels of functional status, it is reasonable that patients entering a hospice with intractable pain may be at a later stage of disease and thus have a shorter length of stay.

It is not possible to determine, for the interval when interventions were performed, whether pain level was measured prior to administering the interventions or after administration. In addition, as was the case with assessing changes in functional status, other interventions not reported because they are not perceived to be high cost may have contributed to changes in patient pain level. Another observation is that, contrary to the belief that patients experiencing intractable pain are those who are receiving interventions considered to be high cost, few of the patients identified as high cost experienced intractable pain during any point in their hospice stay. Patients identified as high cost appear to be receiving sophisticated interventions despite a lower intensity pain level.

Unlike these patterns of some improvement in pain control, other studies have noted decreasing pain control (increased pain) as patients approach death. For example, in the final report of the National Hospice Study (Brown University, 1987), the researchers evaluated the effects of hospice care on pain and other symptoms of cancer patients. They used three pain measures: two involving the primary care provider's assessment

of the individual's pain, and one based on patient self-reporting. Examining pain and discomfort levels for patients at 5 weeks, 3 weeks, and 1 week prior to death, the study found that a higher proportion of patients were free from pain at 5 weeks prior to death than the proportion free from pain at 1 week prior to death (34.6 percent versus 28.6 percent). Also, in the highest pain category, fewer patients experienced severe pain at 5 weeks prior to death than at 1 week prior to death (3.4 percent versus 6.3 percent).

Mix of Days Provided

In an effort to identify whether patients identified as high cost spent a large number of days in types of care other than routine home care, an analysis of the mix of days comprising hospice stays is presented in Table 5-11. Patients identified as high cost are categorized according to whether they had routine home care days only, routine home care days plus days spent in either continuous home care, general inpatient care, or inpatient respite care, or no routine home care days. Slightly less than half of these patients had only routine home care days (48.8 percent), while approximately one-third (35 percent) had routine home care plus at least 1 day of general inpatient care. Just over 2 percent of patients had routine home care plus at least 1 day of continuous home care, while another 2 percent had routine home care days plus at least 1 day of inpatient respite care. Three percent had no routine home care days at all. Most of the 49 patients in the latter group had entirely general inpatient days or some combination of general inpatient, continuous home care, and inpatient respite care days.

Table 5-12 examines this issue from a slightly different perspective. Here patients are assigned to one of the four Medicare hospice payment rate categories according to the category in which they spent the highest proportion of their days. Thus, a patient would be classified into the routine home care category if, for example, 30 percent of their stay was in routine home care days and they spent 20 percent of their stay in each of the other three categories. Of 1,681 patients approximately 94 percent spent the highest proportion of their days in the routine home care category. One percent spent the largest proportion of their days in either continuous home care or inpatient respite care, and 5.4 percent spent the largest proportion of their stay in the general inpatient category.

These findings are generally consistent with rough estimates computed from HCFA data on covered charges for FY 1988. These estimates indicate that routine home care days account for the largest share (approximately 96 percent) of days, while general inpatient days account for approximately 4 percent of total days (HCFA, 1991). Tables 5-11 and 5-12 indicate that while a large proportion of patients spend most of their days in the routine home care category, a large number (at least 37 percent) also have some inpatient days.

Distribution of Diagnoses

Table 5-13 presents the distribution of primary diagnoses for hospice patients identified as high cost. The majority of patients (86.8 percent) have a diagnosis of cancer while less than 15 percent have some other primary diagnosis. For Medicare hospice benefit patients, over half of the cases have a cancer diagnosis associated with either a digestive (25.7 percent) or respiratory (23.9 percent) organ (most likely colon and lung cancer). Other large categories include breast cancer, cancer of male reproductive organs, and cancer of the lymphatic and hematopoietic tissue.

Patients with Human Immunodeficiency Virus (HIV) infection constitute approximately 4 percent of the overall sample of patients identified as high cost, but only about 2 percent of the pool of Medicare hospice patients identified as high cost. This is reasonable since many HIV patients are unlikely to be eligible for Medicare (at least due to the age criterion and the 2-year waiting period after disability determination) and are more likely to have private insurance or Medicaid coverage.

Other than for patients with HIV infection, Medicare hospice beneficiaries do not appear to differ from the overall population of patients identified as high cost. They may be slightly more likely to have cancer associated with male reproductive organs, or bladder and/or kidney cancer, and slightly less likely to have breast cancer, cancer of female reproductive organs, and cancer of nervous system organs.

Medicare home health beneficiaries reveal a slightly different pattern. Approximately 81 percent of these cases have cancer diagnoses; thus, slightly more of these patients have noncancer diagnoses than do the Medicare hospice beneficiaries. Interestingly, a much larger proportion (9.9 percent) have HIV infection.

The distribution for "All Other," which is predominantly private insurance and self-pay patients, is similar to the Medicare hospice distribution, with a slightly higher incidence of HIV infection. The Medicaid distribution, however, is distinctly different. Approximately 71 percent of the Medicaid patients have cancer diagnoses, and there is a much higher proportion of cases with HIV infection and disorders of the immune system. Assuming that AIDS patients are more likely to be covered by Medicaid, particularly after long lengths of stay, these findings are reasonable.

One purpose of this analysis was to identify whether the frequency of interventions performed on patients having certain diagnoses was disproportionately higher than the percent of cases with that diagnosis. If such patterns exist, then certain diagnoses may be indicators of high cost care.

Table 5-13 reveals similarity in the distribution of diagnoses across interventions and cases, thus, it does not appear to be possible to identify high cost cases based on diagnosis alone. This finding corroborates the CAP discussion that using diagnosis as an indicator of high cost might be misleading as characteristics since difficult-to-manage pain are not necessarily associated with particular diagnoses.

5.7 Results: Intervention-Level Analyses

For the sample of 1,681 patients identified as high cost, 3,110 interventions were identified; on average slightly less than two per patient. A series of analyses at the intervention level were conducted. One of the main objectives of this study was to identify high cost interventions and to describe dimensions of their use. In completing the survey, however, providers were not restricted on the types of interventions they could report. As a result, a wide variety of interventions were identified. The 88 hospices responding to the HCIS survey identified over 130 interventions as high cost. In analyzing the data, interventions were assigned to 1 of 12 broad Type of Intervention categories:

- narcotics,
- antibiotics,
- chemotherapy,
- general medications,
- radiation,
- blood therapy,
- hyperalimentation,
- enteral nutrition,
- hydration therapy,
- supplies,
- equipment, and
- surgical and/or medical procedures and visits.

When more specific information was provided, the intervention was also assigned a specific intervention code. Thus, an intervention was included in the general Type of Intervention category, and if enough information was available, in a more precise Specific Intervention category. While most interventions are coded into both categories, some interventions are only coded with a Type of Intervention-level code, depending on the level of information available on the survey form. The frequency distributions for the 12 types of interventions and for the more frequently reported specific interventions, by source of payment, are presented in Tables 5-14a-d.

These tables arrange the Type of Intervention categories into four larger groups: 1) medications (Table 5-14a); 2) different therapies (Table 5-14b); 3) supplies and equipment (Table 5-14c); and 4) procedures and visits (Table 5-14d). On these tables, the general "Type of Intervention" category is capitalized. On Table 5-14d, the procedure subcategories (e.g., radiology, gastrointestinal, etc.) also are capitalized. The Specific Intervention categories are not capitalized. Because they are closely linked, supplies and equipment (Table 5-14c) are discussed below together with medications (Table 5-14a) rather than discussed separately.

Throughout the discussion of these tables it is important to remember that the interventions were self-defined by responding hospices as being high cost. In the absence of other studies indicating the frequency of use for the included interventions, it is difficult to ascertain how representative the frequencies obtained in this analysis are. However, given that some of these interventions are still identified fairly frequently, they may indeed be the types of interventions that truly are costly for hospice providers. In addition, the purpose of these tables was to present, as specifically as possible, the range of interventions identified as high cost. Thus, as with the remaining tables, some of the frequency counts are low. Both the Medicare home health and Medicaid samples are quite small relative to the Medicare hospice and Other payment source categories, however, so potentially distinct patterns of use should be interpreted with caution.

Medications

The most frequently identified interventions involved use of medications (Table 5-14a). Out of all interventions, medications accounted for 42.5 percent, and ranged between 39 percent of interventions provided to Medicare hospice beneficiaries and 47.6 percent for All Other patients. This is driven by frequent use of narcotics, the most frequently identified medications Type of Intervention. This category of medications is used to control moderate to extreme pain. Because pain is a frequent symptom of hospice patients, the high reported use of narcotics is not surprising. Approximately one-fifth (20.3 percent) of the total interventions provided were narcotics. The high use of narcotics ranged from 10 percent of interventions for Medicare home health beneficiaries to approximately 20 percent for the Medicare hospice, Medicaid, and private insurance groups. Morphine is the most frequently mentioned narcotic; and over half of all the narcotic use is accounted for by this agent. Dilaudid, another narcotic, is used less frequently, ranging from less than 1 percent of interventions for Medicaid and Medicare home health patients to 3 percent and just over 5 percent for Medicare hospice and private insurance patients.

The identification of narcotics as high cost treatments supports the literature review findings that this class of medications can potentially be quite costly (Wener, 1988). However, much of the cost associated with providing these agents is due to the delivery

system, not necessarily the drug itself. The widespread identification of these medications as high cost indicates the need for research analyzing the costs of these narcotic analgesics. Unfortunately, other factors that influence drug costs (dosage, frequency of intervention and mode of administration) were not reported consistently in the survey. Without complete and accurate information on these three variables, the associated costs are difficult to determine.

Supplies and equipment are frequently an essential component of narcotic administration, especially when the drug is given intravenously. The survey responses indicated, for example, that supplies and equipment frequently are used in conjunction with morphine. When both the cost of the narcotic and the cost of related supplies and equipment are taken into account, it is possible that the overall costs related to narcotic drug administration are quite high. As shown in Table 5-14c, close to 8 percent of the reported interventions provided to all patients are for intravenous supplies and 6 percent of interventions are for intravenous pumps (including PCA pumps). Both the CAP members and the literature review reported that the cost of PCA pumps alone is much higher than traditional intravenous equipment. The number of interventions related to intravenous drug administration seems to indicate that further research examining these types of interventions is merited.

There appears to be some variation in use of supplies and equipment across sources of payment. Use of IV supplies ranges between less than 1 percent for Medicare home health beneficiaries and 10 percent for patients covered by other sources of payment. Intravenous and PCA pumps together account for 2.5 percent of total interventions provided to Medicare home health beneficiaries, but approximately 7 percent of interventions provided to patients in the All Other source of payment category. The Medicare home health category shows a distinctly lower frequency of use of equipment. Other than supplies and equipment related to IV medication delivery (see Table 5-14c), other specific types of supplies or equipment accounted for less than 1 percent of all interventions.

After narcotics, general medications are the most frequently mentioned medication Type of Intervention (11.9 percent of all interventions), followed by chemotherapy and antibiotics (7.1 and 3.2 percent, respectively). Both general medications and chemotherapy could be further differentiated into Specific Intervention categories. However, very few specific interventions for both of these categories were frequently reported. Within the general medication category, Valium accounted for 4.6 percent of the interventions across all payor categories, 3.4 percent of the interventions provided to Medicare beneficiaries and 7.3 percent of interventions provided to other patients. Two other general medications, AZT and pentamidine, largely associated with AIDS treatment, were reported primarily for Medicaid patients. These medications account for 5.2 percent and 9.6 percent, respectively, of all interventions provided to the Medicaid hospice patients identified as high cost. Specific chemotherapeutic agents

were not reported frequently.

Antibiotics were not identified as high cost as frequently as expected. Although almost all of the Medicare hospices reported using this intervention for some patients on the 1990 annual survey, only 3.2 percent of all interventions and 4.4 percent of interventions provided to Medicare hospice beneficiaries were antibiotics. Although 30 different types of antibiotics were identified as being high cost, the frequency of use for any of these antibiotics was never greater than half a percent.

Types of Therapies

For total patients, types of therapy accounted for 20.5 percent of all interventions (Table 5-14b). Radiation therapy and hydration therapy were the most frequently identified, accounting for 7.4 percent and 6.8 percent, respectively, of all interventions. Radiation therapy was most frequently reported for Medicaid patients (10.4 percent) and least frequently reported for All Other patients (6 percent). Use of hydration therapy ranged from 6 percent of all interventions provided to All Other patients to 7.3 percent of interventions provided to Medicare hospice beneficiaries. Use of blood therapy, accounting for 5.2 percent of all interventions, ranged from 4.1 percent of interventions provided to All Other patients to 7.1 percent for Medicare home health patients.

TPN, another intervention listed on the 1990 NHO's annual survey, also was infrequently reported as a high cost intervention for the HCIS survey (1.1 percent of all interventions). The frequency of another form of nutritional therapy, enteral feedings, also shows that, although identified as a high cost intervention, it is not frequently used. Use of TPN appears to be highest for Medicare home health patients (3.2 percent of all interventions) while use of enteral nutrition appears to be highest for Medicaid patients (3.7 percent of all interventions).

Procedures and Visits

As shown in Table 5-14d, 16 percent of all interventions provided to all patients fall into this category. The procedure and visit category, however, is a broad category. The bulk of the procedures included in this intervention category are hospital or office based medical or surgical techniques (laboratory, surgery, radiology, and medical testing). This category also includes information about physician, nursing and other ancillary service visits. It is interesting to note that, while the proportion of procedures and visits provided to the Medicare hospice population is close to the average for all the patients (19.6 percent), the frequency of procedures and visits is higher for the Medicare home health patients (27.3 percent), and lower for the All Other category (11.2 percent). In many cases, more specific information was not provided for these interventions.

Few of the specific procedures and visits identified by survey respondents as high cost were reported to occur with much frequency. Hospitalizations (listed under other interventions) account for 4.9 percent of all interventions but there is no further information about what specific interventions were provided for these cases. Lack of specific information also is revealed by the relatively large numbers of procedures and visits listed simply as other procedures.

The most commonly reported procedure/visit Specific Intervention was respiratory or oxygen therapy, which accounted for 1.7 percent of all interventions and 2.4 of interventions provided to Medicare hospice patients. Other specific interventions noted frequently were radiology procedures (3 percent of all interventions). The most frequently mentioned radiology procedures include computerized tomography, particularly for the Medicare hospice population (1.9 percent of interventions), and x-ray, particularly for the Medicaid population (3 percent of interventions). Interestingly, hip and bowel obstruction surgery, identified by the CAP as high cost procedures, were mentioned infrequently. These two procedures accounted for less than 1 percent of all interventions.

Intervention Use and Diagnosis

In order to determine whether the frequency of high cost interventions differed by diagnoses, the distribution of interventions provided to patients with cancer diagnoses and those with noncancer diagnoses were compared. The results are summarized in Table 5-15. Digestive and respiratory cancers are separated from the other cancer diagnoses because they constituted over 50 percent of the cancer diagnoses in the sample (see Table 5-13). An attempt was made to identify the patterns of high cost intervention use for the AIDS population by grouping together immune system disorders and HIV infection diagnoses and separating them out from the other noncancer diagnoses.

Comparing these distributions of interventions provided to all cancer and all non-cancer cases (the last two columns on Table 5-15) shows that some of the therapies were reported more frequently for patients with cancer diagnoses. Narcotics, chemotherapy, radiation therapy, and supplies were more frequently cited as interventions provided to patients with cancer diagnoses than to patients with noncancer diagnoses. However, general medications, enteral nutrition, blood therapy, and antibiotics were the more commonly reported high cost interventions for patients with noncancer diagnoses. This pattern is consistent with the types of therapy cancer and noncancer patients receive.

When the subcategories of cancer diagnoses (respiratory, gastrointestinal and all other cancer) and noncancer diagnoses (HIV and other noncancer) are compared against each other, the distribution of interventions also varies. Among the cancer diagnoses, some interventions were associated more frequently with some cancer diagnoses than

others. Use of narcotics, for example, was more frequently reported for digestive cancers (21.7 percent) than for respiratory cancers (17.3 percent). Conversely, use of radiation therapy is much higher for respiratory cancers (12.7 percent) than for digestive cancers (4.4 percent).

Other dissimilarities are found by comparing the distribution of high cost interventions for patients with HIV infection to the distributions for other noncancer and cancer cases. The frequencies of general medication, hydration, and antibiotic interventions were higher for cases with a diagnoses of HIV infection than for either the other non-cancer or cancer diagnoses. General medications accounted for 35.2 percent of the interventions provided to cases with HIV infection, compared to a range of 9.3 to 11.2 percent of interventions provided to cases with other diagnoses. However, equipment and procedural interventions are mentioned as high cost interventions for patients with other noncancer diagnoses more frequently than for patients with either HIV infection or cancer diagnoses.

Intervention Use and Pain Level

Comparing the distribution of interventions by pain status at admission and during the interval when interventions are provided yields several interesting findings (Table 5-16). One of the most interesting findings is that the provision of interventions does not appear to be related to higher intensity pain. The majority of the interventions related to pain control (narcotics and antianxiety agents like Haldol and Valium) are initiated on patients who have only mild to moderate pain at admission and who also do not appear to experience substantial change in pain level after admission. It is also interesting to note that other nonpain related interventions are frequently initiated for the same category of patients (those experiencing mild-moderate pain on admission and when the intervention is provided). It may be possible that the frequency of pain related interventions are higher for patients that fall into the mild-moderate pain category because they have longer lengths of stay in the hospice program.

Several other factors with regard to pain status are puzzling. A surprisingly large percentage of the narcotics interventions (13.7 percent) were initiated when patients reportedly experienced no pain at the time when interventions were provided (5.7 percent of patients with no pain at admission, plus 5.1 percent for patients with mild-moderate pain at admission, plus 2.9 percent for patients with strong-severe pain at admission). Close to 20 percent of the narcotics interventions were provided to patients who experienced less severe pain when the interventions were provided than when they were admitted. However, as with the earlier discussion of pain level and functional status, these results must be interpreted with caution since it is unclear exactly when the intervention was provided.

Intervention Use and Mix of Routine Home Care and General Inpatient Care Days

One assumption made about high cost hospice care is that patients who spend a large proportion of their hospice days using inpatient care are more likely to be high cost cases than are patients who use less inpatient care. An attempt was made to explore this assumption by categorizing patients according to what proportion of their total length of stay was accounted for by days spent in general inpatient care, and comparing the interventions received by these different patient groups. The results for Medicare hospice patients only are presented in Table 5-17.

Comparing the general types of interventions received by patients who had no inpatient days (first column) to those received by patients whose entire hospice stay was spent in inpatient care (the last column), those cases with no inpatient days, narcotics, supplies, equipment, and radiation therapy accounted for the largest proportion of cases (23.2, 11.1, 10.0, and 12.2 percent, respectively). However, there is not a clear pattern of increasing or decreasing use associated with more inpatient days.

For the relatively few patients with only inpatient days were much more likely to receive general medications, particularly valium (12 percent) than were patients with no inpatient days. They were also more likely to receive hydration therapy (16 percent) than were patients with no inpatient days (5.3 percent), and more likely to receive antibiotics. Again, however, there is not a clear pattern of increasing or decreasing use associated with a higher or lower proportion of days spent in inpatient care. Thus, looking across the categories of patients with increasing proportions of their hospice stay spent in general inpatient care, patterns of intervention use are not apparent.

5.8 Summary of Survey Data Analyses

Despite the limitations of the survey data, several observations can be made about what hospice providers have identified as high cost care. First, a major objective of the data analysis was to identify the interventions that are high cost. Ranking the interventions most frequently reported by responding hospices yields the following: a ranking of the broad Type of Intervention categories, and a ranking of the Specific Intervention categories. For the Type of Intervention, any one accounting for over 5 percent of all interventions is included. For Specific Interventions, any one accounting for over 1 percent of all interventions is included.

Type of Intervention Ranking		Specific Intervention Ranking	
Intervention	% Reported	Intervention	% Reported
1. Narcotics	20.3%	1. Morphine	11.5%

2. Procedures/ Visits	16.0	2. IV Supplies	7.9
3. Supplies	12.9	3. IV/PCA Pumps	6.0
4. General Meds	11.9	4. Valium	4.6
5. Radiation Therapy	7.4	5. Dilaudid	3.5
6. Equipment	7.3	6. IV Pumps	1.7
7. Chemotherapy	7.1	7. Respiratory Therapy	1.7
8. Hydration Therapy	6.8	8. Computerized Tomography	1.2
9. Blood Therapy	5.2	9. Packed Cells	1.1

These rankings illustrate that narcotics are frequently identified as a high cost intervention. In fact, narcotics were reported approximately 650 times out of a total of 3,131 interventions. Over half of these narcotic interventions can be attributed to morphine use. The second most commonly used narcotic is dilaudid accounting for 15 percent of the narcotic use. Intravenous supplies and equipment (both general intravenous and PCA pumps) that are often complementary to the administration of narcotics are also ranked among the most frequently reported interventions.

Narcotics and their associated means of drug delivery were commonly reported interventions in the hospice literature review. Expert panel findings also indicated that intravenous narcotic use can be high cost. Since all three data sources seem to reaffirm that this type intervention can be quite costly, future work should be aimed at appropriately identifying what factors more strongly influence the high cost of this intervention. It is not known precisely whether the high cost of the intervention is related to the drug itself, in which case, items like the route of administration, the duration of the therapy, and the dosage of the medication would more strongly influence cost and/or whether the costs are due to some of the associated maintenance costs such as nursing visits, and equipment and supply costs.

The survey results also identify radiation therapy and some procedures as high cost interventions. There appears to be some agreement between the survey results and the expert panel findings that palliative radiation therapy may be a high cost intervention. However, not all the interventions identified by the panelists and by the survey results are identical. Two surgical procedures identified by the panelists as high cost were hip surgery and bowel obstruction surgery. However, the above ranking of specific interventions shows that these two surgeries are not among the most frequently reported interventions.

In addition, although the panelists believed that the cost impact of hyperalimentation and antibiotic use was significant, the survey results indicate that these interventions were not frequently reported as high cost. Therefore, these interventions (bowel

obstruction surgery, hip surgery, antibiotics, and hyperalimentation therapy) are identified as high cost but they may not be as frequently performed as other types of interventions identified as high cost.

A second objective of the survey data analysis was to gather information about the characteristics of hospice patients identified as high cost (or receiving interventions identified as high cost). Although the intervention-level information, when classified by source of payment, revealed what some of these distinctions are, other case-level characteristics (demographic, length of stay, and diagnoses) reveal potentially more subtle differences among these patients. Table 5-18 is a summary table of selected distributions discussed earlier, by source of payment. The percents in this table might be slightly different than the percents in corresponding earlier tables, depending on how the cases with missing information on the selected characteristics are incorporated.

In summarizing the demographic characteristics, the Medicare hospice and home health patients are similar (the majority are elderly and white), while the Medicaid patients are younger and of different ethnic origins. The All Other patients are also younger, but again are mostly white. These patterns seem to be consistent with the populations covered by these payment sources, and, thus, demographic characteristics do not appear to distinguish the potentially high cost cases from other cases.

While the Medicare hospice and home health patient samples reveal a similar proportion of cases with cancer diagnoses and similar average lengths of stay, the home health patients appear to receive more interventions on a per case basis (2.1 compared to 1.7). Comparing the reported Medicare hospice intervention information with the three other types of payers shows that this group ranks the highest in the reported frequency of antibiotic use. This payor group reported use of supplies (22.4 percent) and equipment (13.2 percent) also is higher than what was noted for the Medicare home health and Medicaid samples.

Procedures and radiation therapy were more frequently identified for Medicare home health cases than for the other three source of payment categories. Hyperalimentation and blood therapy were also more frequently identified for Medicare home health patients.

The All Other source of payment category, which includes predominantly patients covered by private insurance plans, have the shortest average length of stay (63 days). For this group, the short length of stay seems to have no bearing on the frequency of services provided. The number of interventions per case is similar to that for Medicare home health beneficiaries. Narcotics, general medications and supplies are identified more frequently for these cases than for Medicare or Medicaid patients.

Even though cancer diagnoses still account for most Medicaid cases, a higher percentage (30 percent of the total cases) have noncancer diagnoses. The frequency of enteral nutrition use is higher for Medicaid cases. Compared to the Medicare population, the reported frequency of narcotic use and general medication use, especially pentamidine and AZT, is also higher.

Thus, according to these data, there are differences in the frequency of use of various interventions across patients in different source of payment categories. However, it is difficult to state why these differences appear, other than that they reflect the different populations covered by these sources of payment. In addition, some of the difference in the use of interventions is more likely to be driven by the different diagnoses (and thus different treatment patterns) associated with the populations covered by these sources. Finally, data concerns limit the generalizability of any of these patterns to the larger population.

TABLE 5-1: Percentages of Hospices Providing Interventions Identified High Cost, by Medicare and Respondent Status

	1990 NHO ANNUAL SURVEY		HIGH COST INTERVENTION STUDY SURVEY	
INTERVENTION	All Hospices (N=1,766)	All Medicare-Certified Hospices (N=653)	All Medicare-Certified Hospices Providing High Cost Interventions (N=508)	All Medicare-Certified Hospices Providing High Cost Interventions That Responded (N=508)
Any	55.1	77.6	--	--
All	1.3	1.4	--	--
Antibiotics	50.1	72.9	93.9	96.6
AET	19.0	26.8	34.4	32.2
Dialysis	5.8	5.7	7.3	10.3
EPO	2.7	3.2	4.1	2.3
Morphine Pump	49.0	69.7	89.8	96.6
Palliative Chemotherapy	34.1	49.9	64.4	74.7
Palliative Radiation	34.3	52.4	67.5	82.8
Surgery	19.0	28.6	36.8	40.2
TPN	10.1	22.2	28.7	26.4

Source: Project HOPE computations based on NHO Annual Survey data for hospices responding to the HCIS survey.

Note: The third column represents all hospices responding "Yes" to providing at least one of the nine interventions listed in the last question on the 1990 NHO annual survey. These 508 hospices were sent the second questionnaire requesting cost and use information on these interventions. Eighty-eight hospices responded to the second questionnaire.

TABLE 5-2: Organizational Base of Hospices Responding to the HCIS Survey and all Medicare-certified Hospices

	Hospices Responding to the HCIS SURVEY		Medicare-Certified Hospices_1	
ORGANIZATIONAL BASE	Number	Percent	Number	Percent
Hospital	19	22.6%	253	28.2%
Home Health Agency	12	14.3	342	38.1
Nursing Home	0	0.0	13	0.0
Independent	50	59.5	290	32.3
Coalition	1	1.2	-	-
Other	2	2.4	-	-
Missing	4	-	-	-
TOTAL	88	100.0%_2	898	100.0%

Source: Project HOPE computations based on NHO Annual Survey data for hospices responding to the HCIS survey.

_1 HCFA data as of December 1990

_2 100.0% of hospices providing organizational base information for the NHO Annual Survey, excluding those with missing information.

TABLE 5-3: Hospice Facility Size: Total Number of Patients Admitted to Hospices Responding to the HCIS Survey

NUMBER OF PATIENTS ADMITTED	Responding Hospices	
	Number	Percent
1-9	0	0.0%
10-24	5	6.0
25-49	5	6.0
50-99	18	21.7
100-199	32	38.6
200-499	18	21.7
500	5	6.0
Missing	5	---
TOTAL	88	100.0%_1

Source: Project HOPE computations based on NHO Annual Survey data for hospices responding to the HCIS survey.

_1 100.0% of hospices providing information on the number of patients admitted on the NHO Annual Survey, excluding those with missing information.

TABLE 5-4: Total Number of Medicare Patients Admitted in 1989 to Hospices Responding to the HCIS Survey

NUMBER OF MEDICARE PATIENTS	Hospices Responding to HCIS Survey		Medicare-Certified Hospices_1	
	Number	Percent	Number	Percent
0	9	10.8%	-	-
1-9	3	3.6	97	12.7%
10-24	8	9.6	137	18.0
25-49	10	12.0	167	22.0
50-99	26	31.3	173	22.8
100-199	19	22.9	117	15.4
200-499	8	9.6	56	7.4
500	0	0.0	13	1.7
Missing	5	---	-	-
TOTAL	88	100.0%_2	760	100.0%

Source: Project HOPE computations based on NHO Annual Survey data for hospices responding to the HCIS Survey

_1 HCFA data for 1989

_2 100.0% of hospices providing information on the number of Medicare beneficiaries admitted on the NHO Annual Survey, excluding those with missing information.

TABLE 5-5: Percent (Number of Medicare-certified Hospices With Varying Proportions of Total Patient Caseload Identified as High Cost By ZIP Code National Area

ZIP CODE NATIONAL AREAS_1	Proportion of Total Case Load Identified As High Cost					Number of Medicare-Certified Hospices Responding to HCIS in Area_2	Total Number of Medicare-Certified Hospices in Area_3	Respondent Hospices as a Percent of Medicare-Certified Hospices
	< 10%	10-14%	15-19%	20-24%	25% and over			
0	60.0%	0.0%	20.0%	0.0%	20.0%	5	70	7.1 %
1	60.0	30.0	0.0	0.0	10.0	10	82	12.2
2	46.7	26.7	6.7	6.7	13.3	15	76	19.7
3	70.0	10.0	0.0	20.0	0.0	10	96	10.4
4	60.0	6.7	20.0	0.0	13.3	15	93	16.1
5	25.0	12.5	0.0	12.5	50.0	8	65	12.3
6	100.0	0.0	0.0	0.0	0.0	5	59	8.5
7	100.0	0.0	0.0	0.0	0.0	3	75	4.0
8	20.0	20.0	40.0	20.0	0.0	5	54	9.3
9	16.7	33.3	16.7	16.7	16.7	6	86	7.0
OVERALL _4	53.7% (44)	15.9% (13)	9.8% (8)	7.3% (6)	13.4% (11)	82 _5	756	10.8 %

Source: Project HOPE computations based on NHO Annual Survey and HCIS survey data.

_1 Areas of the U.S. where ZIP codes begin with this number (e.g., Area 2 includes the District of Columbia, Maryland, and Virginia).

_2 Row percents are percents of this number.

_3 HCFA data of the number of Medicare-certified hospices in existence for 1989.

_4 Calculated as a percent of 82 hospices reporting this information.

_5 The total number of Medicare-certified hospices responding to the HCIS survey is 88. Of this total, only 82 furnished information about their total caseload.

TABLE 5-8: Number and Percent of Cases Identified as High Cost by Sex, Age, Ethnic Background and Source of Payment at Admission

DEMOGRAPHIC CHARACTERISTIC	Total		Medicare Hospice		Medicare Home Health		Medicaid_1		All Other_2	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Sex										
Male	894	53.2 %	528	54.2 %	48	48.0 %	41	49.4 %	270	54.1 %
Female	748	44.5	428	43.9	52	52.0	39	47.0	219	43.9
Missing	39	2.3	18	1.8	0	0.0	3	3.6	10	2.0
Age										
65 and over	1,078	64.1 %	875	89.8 %	83	83.0 %	7	8.4 %	102	20.4 %
50-64	318	18.9	56	5.7	3	3.0	17	20.5	239	47.9
35-49	168	10.0	20	2.1	12	12.0	36	43.4	97	19.4
20-34	56	3.3	2	0.2	1	1.0	18	21.7	35	7.0
Under 20	15	0.9	1	0.1	1	1.0	1	1.2	12	2.4
Missing	46	2.9	20	2.1	0	0.0	4	4.8	14	2.8
Ethnic Background										
White	1,507	89.6 %	896	92.0 %	90	90.0 %	59	71.1 %	447	89.6 %
Hispanic	34	2.0	13	2.0	5	5.0	8	9.6	8	1.6
Black	70	4.2	31	3.2	4	4.0	11	13.3	22	4.4
Other_3	70	4.2	34	3.5	1	1.0	5	6.0	22	4.4
TOTAL CASES_4	1,681		974		100		83		499	

Source: Project HOPE computations based on HCIS survey data.

_1 Home Health and Hospice cases combined

_2 Health Insurance, Self-Pay, and Indigent combined (health insurance patients account for the largest number of patients)

_3 "Other" includes patients who are native American, Alaskan native, or Asian as well as missing information

_4 Number for each source of payment category do not add up to 1,681 cases; source of payment at admission was not reported for 25 cases.

TABLE 5-7: Source of Payment At Admission, During Interval When Interventions Provide and at Discharge for Cases Identified as High Cost

SOURCE OF PAYMENT	Percent of Cases at Point of Assessment		
	At Admission	During Interval When Interventions Provided	At Discharge
Medicare Hospice	58.8 %	61.8 %	60.1 %
Medicare Home Health	6.0	4.4	4.7
Medicaid Hospice	3.0	3.6	3.5
Medicaid Home Health	2.0	2.0	1.8
Health Insurance	24.0	23.8	23.7
Self-Pay	1.9	1.3	1.8
Indigent	4.2	3.1	4.3
TOTAL	100.0%	100.0%	100.0%
Number of Cases_1	1,656	1,604	1,622

Source: Project HOPE computations based on HCIS survey data.

_1 Number of cases where payment source is identified at relevant point of assessment (total number of cases is 1,681).

Note: Percents may not add exactly to 100.0 due to rounding.

TABLE 5-8: Number and Percent of Cases Identified as High Cost by Source of Payment When Interventions Were Performed and Length of Stay (LOS) Category

LENGTH OF STAY (days)	Medicare Hospice		Medicare Home Health		Medicaid Hospice		Medicaid Home Health		Health Insurance		Self-Pay		Indigent	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
1-7	84	8.6%	2	3.7%	2	3.5%	0	0.0%	43	11.4%	1	5.0%	3	6.3%
8-14	76	7.8	5	9.3	5	8.8	2	6.3	38	10.1	0	0.0	3	6.3
15-21	83	8.5	6	11.1	3	5.3	4	12.5	27	7.1	2	10.0	0	0
22-30	71	7.3	5	9.3	9	15.8	3	9.4	43	11.5	4	20.0	5	10.4
31-45	96	9.8	8	14.8	1	1.8	2	6.3	47	12.4	3	15.0	8	16.7
46-60	87	8.9	6	11.1	2	3.5	4	12.5	33	8.8	0	0.0	5	10.6
61-90	143	14.7	5	9.3	13	22.8	2	6.3	44	11.6	2	10.0	7	14.6
91-120	77	7.9	5	9.3	6	10.5	2	6.3	30	8.0	3	15.0	4	8.3
121-180	111	11.4	4	7.4	5	8.8	2	6.3	35	9.3	0	0.0	6	12.5
181-210	29	3.0	1	1.9	2	3.5	4	12.5	9	2.4	1	5.0	1	2.1
Over 210	118	12.1	7	13.0	9	15.8	7	21.9	28	7.4	4	20.0	6	12.5
TOTAL	975	100.0%	54	100.0%	57	100.0%	32	100.0%	377	100.0%	20	100.0%	48	100.0%
AVERAGE LOS	88		89		110		147		72		98		93	
MEDIAN LOS	58		45		79		69		41		44		59	

Source: Project HOPE computations based on HCIS survey data.

Note: Percents may not add exactly to 100.0% due to rounding

TABLE 5-9: Percent (Number) of Cases Identified at High Cost who are Ambulatory, Intermittent Ambulatory, or Nonambulatory During the Interval when Interventions were Provided or at Discharge, by Functional Status at Admission

FUNCTIONAL STATUS AT ADMISSION	Functional Status When Interventions Provided				Functional Status at Discharge_1			
	Ambulatory	Intermittent Ambulatory	Nonambulatory	Total Patients_2	Ambulatory	Intermittent Ambulatory	Nonambulatory	Total Patients_2
Ambulatory	28.3 % (203)	57.0 % (409)	14.6 % (105)	45.6 % (717)	8.9 % (63)	10.7 % (76)	80.4 % (569)	44.3 % (708)
Intermittent Ambulatory	1.0 (5)	61.3 (307)	37.7 (189)	31.8 (501)	2.1 (11)	9.8 (51)	88.1 (458)	32.5 (520)
Non-Ambulatory	0.3 (1)	4.2 (15)	95.5 (340)	22.6 (356)	1.1 (4)	2.2 (8)	96.8 (360)	23.3 (372)
TOTAL	13.3 (209)	46.4 (731)	40.3 (634)	100.0 % (1,574)	4.9 (78)	8.4 (135)	86.7 (1,387)	100.0 % (1,600)

Source: Project HOPE computations based on HCIS survey data.

_1 Measurement assumed immediately prior to discharge.

_2 Total number of cases where functional status at the relevant assessment point was reported.

Note: Percents may not add exactly to 100.0% due to rounding.

TABLE 5-10: Percent (Number) of Cases Identified as High Cost who had No Pain, Mild-Moderate Pain, Strong-Severe Pain, or Intractable Pain During the Interval when Interventions Were Provided or at Discharge, by Pain Level at Admission

PAIN LEVEL AT ADMISSION	Pain Level When Interventions Provided					Pain Level At Discharge _1				
	No Pain	M-M_2 Pain	S-S_2 Pain	Intractable Pain	Total Patients_3	No Pain	M-M Pain	S-S Pain	Intractable Pain	Total Patients_3
No Pain	57.9 % (210)	31.7 % (115)	9.4 % (34)	1.1 % (4)	23.2 % (363)	70.4 % (255)	24.6 % (89)	4.7 % (17)	0.3 % (1)	23.2 % (362)
Mild-Moderate Pain	12.0 (98)	55.3 (451)	29.9 (244)	2.8 (23)	52.2 (816)	38.7 (315)	41.6 (339)	17.5 (143)	2.2 (18)	52.3 (815)
Strong-Severe Pain	10.4 (36)	32.9 (114)	51.4 (178)	5.2 (18)	22.2 (346)	35.1 (121)	24.9 (86)	35.9 (124)	4.1 (14)	22.1 (345)
Intractable Pain	5.4 (2)	24.3 (9)	21.6 (8)	48.6 (18)	2.4 (37)	27.0 (10)	37.8 (14)	5.4 (2)	29.7 (11)	2.4 (37)
TOTAL	22.2 (346)	44.1 (689)	29.7 (464)	4.0 (63)	100.0 % (1,562)	45.0 (701)	33.9 (528)	18.3 (286)	2.8 (44)	100.0 % (1,559)

Source: Project HOPE computations based on HCIS survey data.

_1 Measurement assumed immediately prior to discharge.

_2 M-M = mild-moderate, S-S = strong-severe

_3 Total number of cases where pain level at the relevant assessment point was reported.

Note: Percents may not add exactly to 100.0% due to rounding.

TABLE 5-11: Number and Percent of Cases Identified as High Cost by Days Spent in Different Medicare Hospice Payment Rate Categories

HOSPICE PAYMENT RATE CATEGORIES	Cases	
	Number	Percent
Routine Home Care Days Only	820	48.8 %
Routine Home Care and Continuous Home Care Days	39	2.3
Routine Home Care and General Inpatient Care Days	588	35.0
Routine Home Care and Inpatient Respite Care Days	37	2.2
No Routine Home Care Days	49	2.9
Other_1	148	8.8
TOTAL	1,681	100.0 %

Source: Project HOPE computations based on HCIS survey data.

_1 "Other" includes patients who only had days in either continuous home care, general inpatient care, or inpatient respite care categories, or combinations of categories not presented in this table.

TABLE 5-12: Number and Percent of Cases Identified as High Cost by Medicare Hospice Payment Category in which Highest Proportion of Days were Spent

HOSPICE PAYMENT RATE CATEGORIES	HCIS Cases		Medicare _1
	Number	Percent	Percent
Routine Home Care	1,573	93.6%	95.8%
Continuous Home Care	14	0.8	0.3
General Inpatient Care	90	5.4	3.6
Inpatient Respite Care	4	0.2	0.3
TOTAL	1,681	100.0%	100.0%

Source: Project HOPE computations based on HCIS survey data.

_1 HCFA Office of Research and Demonstration 1988 estimates.

TABLE 5-13: Percent of Interventions and Percent of Cases Identified as High Cost by Primary Cancer Diagnosis and Source Payment

PRIMARY DIAGNOSIS	Total		Medicare Hospice		Medicare Home Health		Medicaid_1		All Other_2	
	Percent of Interventions	Cases	Percent of Interventions	Cases	Percent of Interventions	Cases	Percent of Interventions	Cases	Percent of Interventions	Cases
CANCER DIAGNOSES										
Lip, Oral Cavity, and Pharynx	0.9 %	1.1 %	1.0%	1.2 %	0.0%	0.0	0.0%	0.0 %	1.2%	1.5
Digestive Organs and Peritoneum	23.4	23.6	24.6	25.7	9.2	11.3	20.0	16.9	24.5	22.3
Respiratory and Intrathoracic Or	21.1	22.1	22.2	23.9	23.0	21.1	13.5	14.6	17.4	18.5
Bone and Articular Cartilage	0.5	0.6	0.4	0.5	0.7	1.4	0.6	1.1	0.6	0.7
Connective and Other Soft Tissue	0.6	0.5	0.1	0.2	0.0	0.0	1.3	2.2	1.6	1.1
Skin	1.4	1.1	0.6	0.6	1.3	1.4	0.0	0.0	2.7	2.2
Breast	8.4	8.0	7.7	6.7	12.5	8.5	11.6	14.6	8.6	9.7
Female Reproductive Organs	4.5	4.2	3.7	3.2	8.6	5.6	4.5	5.6	5.4	5.7
Male Reproductive Organs	8.6	8.0	11.6	10.1	7.2	7.0	3.2	4.5	4.6	4.9
Bladder and Kidney	3.8	3.7	4.2	4.5	2.0	2.8	3.2	2.2	3.6	2.9
Eye, Brain, and Other Nervous System	3.4	3.0	2.0	1.9	0.7	1.4	3.9	4.5	6.3	5.1
Thyroid and Endocrine Glands	0.2	0.2	0.0	0.0	0.0	0.0	0.0	0.0	0.6	0.7
Other and Ill-Defined Sites	1.3	1.1	1.4	1.1	1.3	2.8	0.0	0.0	1.3	1.1
Lymph Nodes: secondary, unspecif	0.1	0.1	0.1	0.1	0.0	0.0	0.0	0.0	0.0	0.0
Respirstory/Digestive: secondary	0.5	0.6	0.2	0.3	2.0	2.8	0.0	0.0	0.6	0.7
Other: secondary	0.6	0.8	0.6	0.8	0.7	1.4	0.0	0.0	0.9	0.9
Unspecified	1.4	1.2	1.0	1.2	2.0	1.4	0.0	0.0	1.7	1.3
Lymphatic and Hematopoietic Tissue	5.6	5.7	6.5	6.1	5.9	8.5	3.2	3.4	4.3	4.9
Carcinoma in Situ	0.5	0.5	0.1	0.1	3.9	4.2	2.6	1.1	0.5	0.7
TOTAL CANCER	86.8	86.1	88.0	88.2	81.0	81.6	67.6	70.7	86.4	84.9
Number Interventions/Cases	(2,699)	(1,367)	(1,512)	(859)	(124)	(58)	(105)	(63)	(856)	(385)

TABLE 5-13 (cont): Percent of Interventions and Percent of Cases Identified as High Cost by Primary Noncancer Diagnosis and Source of Payment

PRIMARY DIAGNOSIS	Total		Medicare Hospice		Medicare Home Health		Medicaid_1		All Other_2	
	Percent of Interventions	Cases	Percent of Interventions	Cases	Percent of Interventions	Cases	Percent of Interventions	Cases	Percent of Interventions	Cases
NON-CANCER DIAGNOSES										
Disorders of Immune System	1.5%	1.1 %	0.7%	0.3 %	0.7%	1.4%	19.4%	13.5 %	0.5%	0.7
Diseases of Circulatory System	0.3	0.3	0.5	0.4	0.0	0.0	0.0	0.0	0.1	0.2
Cerebrovascular Disease	0.8	0.4	1.3	0.6	0.0	0.0	0.0	0.0	0.2	0.2
Pulmonary Disease	0.7	1.0	1.0	1.3	0.7	1.4	0.0	0.0	0.2	0.4
Gastrointestinal Disease	0.4	0.5	0.3	0.5	0.0	0.0	0.6	1.1	0.5	0.2
Human Immunodeficiency Virus Infection	4.4	4.2	2.3	2.1	12.5	9.9	9.0	11.2	5.9	5.5
ALL OTHER	3.2	3.7	4.0	3.9	4.6	5.6	2.6	2.2	2.5	3.3
TOTAL NON-CANCER	13.2	13.9	12.0	11.8	18.5	18.3	31.6	28.0	9.9	10.5
Number Interventions/Cases	(411)	(221)	(206)	(115)	(28)	(13)	(49)	(25)	(98)	(48)
Missing	2.3	2.8	2.2	2.5	0.7	0.0	0.6	1.1	3.3	4.4
	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
TOTAL NUMBER OF INTERVENTIONS/CASES	3,110	1,588	1,718	991	152	71	155	89	974	453

TABLE 5-14a: Frequency and Percent of Medication Use by Source of Payment When Interventions Provided

	Medicare Hospice		Medicare Home Health		Medicaid		All Other		Missing		Total	
	#	%	#	%	#	%	#	%	#	%	#	%
TOTAL INTERVENTIONS	1,758		154		135		1,054		30		3,131	
MEDICATIONS _1	686	39.0%	68	44.2%	64	47.4%	502	47.6%	11	36.7%	1,331	42.5%
NARCOTICS	371	21.1 %	15	9.7 %	28	20.7 %	218	20.7 %	3	10.0 %	635	20.3
Morphine Sulfate	220	12.5	12	7.8	15	11.1	112	10.6	2	6.7	361	11.5
Dilaudid	53	3.0	1	0.6	1	0.7	56	5.3	0	0.0	111	3.5
Phenobarb	1	0.1	0	0.0	0	0.0	4	0.4	0	0.0	5	0.2
Demoral	0	0.0	0	0.0	0	0.0	2	0.2	0	0.0	2	0.1
Other narcotic	11	0.6	1	0.6	0	0.0	9	0.9	0	0.0	21	0.7
ANTIBIOTICS	75	4.3 %	3	1.9 %	0	0.0 %	22	2.1 %	1	0.0 %	100	3.2
Amikacin	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Amphotericin	0	0.0	0	0.0	0	0.0	4	0.4	0	0.0	4	0.1
Ampicillin	7	0.4	0	0.0	0	0.0	1	0.1	0	0.0	8	0.3
Ancef	4	0.2	0	0.0	0	0.0	3	0.3	0	0.0	7	0.2
Bactim	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Cefobid	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Cefoxitin	3	0.2	0	0.0	0	0.0	0	0.0	0	0.0	3	0.1
Cipro	0	0.0	0	0.0	0	0.0	1	0.1	0	0.0	1	0.0
Cleocin	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Ceftriaxone	0	0.0	0	0.0	0	0.0	1	0.1	0	0.0	1	0.0
Emycin	0	0.0	0	0.0	0	0.0	1	0.1	0	0.0	1	0.0
Erythromycin	0	0.0	0	0.0	0	0.0	1	0.1	0	0.0	1	0.0
Flagyl	1	0.1	0	0.0	0	0.0	0	0.0	0	0.0	1	0.0
Fortaz	3	0.2	0	0.0	0	0.0	4	0.4	0	0.0	7	0.2
Gentamycin	5	0.3	0	0.0	0	0.0	3	0.3	0	0.0	8	0.3

TABLE 5-14a (cont): Frequency and Percent of Medication Use by Source of Payment When Interventions Provided

	Medicare Hospice		Medicare Home Health		Medicaid		All Other		Missing		Total	
	#	%	#	%	#	%	#	%	#	%	#	%
Kefzol	2	0.1	0	0.0	0	0.0	0	0.0	0	0.0	2	0.1
Mezlocillin	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Naficillin	2	0.1	0	0.0	0	0.0	0	0.0	0	0.0	2	0.1
Penicillin	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Pipercillin	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Septra	1	0.1	0	0.0	0	0.0	0	0.0	0	0.0	1	0.0
Ticarcillin	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Tobramycin	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Unasyn	3	0.2	1	0.6	0	0.0	3	0.3	0	0.0	7	0.2
Vancomycin	1	0.1	0	0.0	0	0.0	0	0.0	0	0.0	1	0.0
Zinacef	9	0.5	0	0.0	0	0.0	2	0.2	0	0.0	11	0.4
Other antibiotic	6	0.3	1	0.6	3	2.2	3	0.3	0	0.0	13	0.4
CHEMOTHERAPY	90	5.1 %	41	26.6 %	13	9.6 %	79	7.5 %	0	0.0 %	223	7.1
Adriamycin, doxorubicin	0	0.0	4	2.6	0	0.0	1	0.1	0	0.0	5	0.2
Cisplatin, plantinol	0	0.0	2	1.3	0	0.0	1	0.1	0	0.0	3	0.1
Mitomycin, mutamycin	0	0.0	4	2.6	0	0.0	0	0.0	0	0.0	4	0.1
Floxuridine, FUDR	0	0.0	1	0.6	0	0.0	0	0.0	0	0.0	1	0.0
Cyclophosphamide, +	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Carmustine, BICNO, +	0	0.0	1	0.6	0	0.0	1	0.1	0	0.0	2	0.1
Lomustine, CeeNU	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Methotrexate, maxate, +	0	0.0	0	0.0	0	0.0	1	0.1	0	0.0	1	0.0
Fluorouracil, adrucil	0	0.0	1	0.6	0	0.0	2	0.2	0	0.0	3	0.1
Other chemo agent	10	0.6	2	1.3	5	3.7	7	0.7	0	0.0	24	0.8
GENERAL MEDICATIONS	150	8.5 %	9	5.8 %	23	17.0 %	183	17.4 %	8	26.7 %	373	11.9
Aminophylline	1	0.1	0	0.0	0	0.0	0	0.0	0	0.0	1	0.0
Ativan	3	0.2	0	0.0	0	0.0	5	0.5	0	0.0	8	0.3
Atropine	2	0.1	0	0.0	0	0.0	2	0.2	0	0.0	4	0.1

TABLE 5-14a (cont): Frequency and Percent of Medication Use by Source of Payment When Interventions Provided

	Medicare Hospice		Medicare Home Health		Medicaid		All Other		Missing		Total	
	#	%	#	%	#	%	#	%	#	%	#	%
AET	4	0.8	2	1.3	7	5.2	10	0.9	0	0.0	23	0.7
Compazine	0	0.0	1	0.6	0	0.0	1	0.1	0	0.0	2	0.1
Decadron	0	0.0	0	0.0	0	0.0	6	0.6	0	0.0	6	0.2
DHPG	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Digoxin	1	0.1	0	0.0	0	0.0	0	0.0	0	0.0	1	0.0
Dilantin	4	0.2	0	0.0	0	0.0	4	0.4	1	3.3	9	0.3
Haldol	5	0.3	0	0.0	0	0.0	13	1.2	2	6.7	20	0.6
Heparin	0	0.0	0	0.0	0	0.0	1	0.1	0	0.0	1	0.0
Lasix	11	0.6	2	1.3	0	0.0	0	0.0	0	0.0	13	0.4
Pentamidine	0	0.0	1	0.6	13	9.6	9	0.9	0	0.0	23	0.7
Polypharmacy	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Potassium	1	0.1	0	0.0	0	0.0	1	0.1	0	0.0	2	0.1
Reglan	2	0.1	0	0.0	0	0.0	1	0.1	0	0.0	3	0.1
Sandoestatin	1	0.1	0	0.0	1	0.7	1	0.1	0	0.0	3	0.1
Solucortef	4	0.2	0	0.0	0	0.0	4	0.4	0	0.0	8	0.3
Solumedrol	2	0.1	0	0.0	0	0.0	1	0.1	0	0.0	3	0.1
Valium	60	3.4	2	1.3	0	0.0	77	7.3	4	13.3	143	4.6
Zantac	2	0.1	0	0.0	0	0.0	1	0.1	0	0.0	3	0.1
Other	20	1.1	1	0.6	2	1.5	20	1.9	1	3.3	44	1.4

Source: Project HOPE computations based on HCIS survey data.

_1 Measured as a percent of total interventions

TABLE 5-14b: Frequency and Percent of Specific Therapies by Source of Payment When Interventions Provided

	Medicare Hospice		Medicare Home Health		Medicaid		All Other		Missing		Total	
	#	%	#	%	#	%	#	%	#	%	#	%
TOTAL INTERVENTIONS	1,758		154		135		1,054		30		3,131	
TOTAL THERAPIES _1	374	21.3 %	40	26.0 %	32	23.7 %	188	17.8 %	7	23.3 %	641	20.5
RADIATION THERAPY	137	7.8 %	15	9.7 %	14	10.4 %	63	6.0 %	2	6.7 %	231	7.4
BLOOD THERAPY	99	5.6 %	11	7.1 %	8	5.9 %	43	4.1 %	2	6.7 %	163	5.2
Packed Cells	20	1.1	4	2.6	2	1.5	8	0.8	0	0.0	34	1.1
Platelets	3	0.2	1	0.6	0	0.0	2	0.2	0	0.0	6	0.2
Fresh Frozen Plasma	1	0.1	0	0.0	0	0.0	0	0.0	0	0.0	1	0.0
Albumin	0	0.0	0	0.0	0	0.0	1	0.1	0	0.0	1	0.0
Other	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
HYPERALIMENTATION (TPN)	9	0.5 %	5	3.2 %	1	0.7 %	19	1.8 %	0	0.0 %	34	1.1
Amino Acid Only	1	0.1	0	0.0	0	0.0	1	0.1	0	0.0	2	0.1
Carbohydrates Only	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Amino Acid + Carbohydrates	1	0.1	0	0.0	0	0.0	0	0.0	0	0.0	1	0.0
Lipids	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Other	1	0.1	1	0.6	0	0.0	4	0.4	0	0.0	6	0.2
ENTERAL NUTRITION	27	1.5 %	2	1.3 %	5	3.7 %	11	1.0 %	0	0.0 %	45	1.4
Pulmocare +	1	0.1	0	0.0	0	0.0	1	0.1	0	0.0	2	0.1
Compleat B +	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Magnecal +	0	0.0	0	0.0	1	0.7	0	0.0	0	0.0	1	0.0
Criticare HN +	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Hepatic +	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
ProPAC +	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Vivonex STD +	1	0.1	0	0.0	0	0.0	0	0.0	0	0.0	1	0.0
Osmolite	8	0.5	0	0.0	1	0.7	2	0.2	0	0.0	11	0.4
Other	8	0.3	0	0.0	0	0.0	0	0.0	0	0.0	6	0.2
HYDRATION THERAPY	129	7.3 %	9	5.8 %	9	6.7 %	63	6.0 %	3	10.0 %	213	6.8

Source: Project HOPE computations based on HCIS survey data.

TABLE 5-14c: Frequency and Percent of Supplies and Equipment by Source of Payment When Interventions Provided

	Medicare Hospice		Medicare Home Health		Medicaid		Other		Missing		Total	
	#	%	#	%	#	%	#	%	#	%	#	%
TOTAL INTERVENTIONS	1,758		154		135		1,054		30		3,131	
TOTAL SUPPLIES/ EQUIPMENT _1	353	20.1 %	8	5.2 %	17	12.6 %	246	23.3 %	6	20.0 %	630	20.1 %
SUPPLIES	222	12.6 %	3	1.9 %	8	5.9 %	165	15.7 %	5	16.7 %	403	12.9 %
IV	132	7.5	1	0.6	3	2.2	106	10.1	4	13.3	246	7.9
Respiratory	7	0.4	1	0.6	1	0.7	4	0.4	0	0.0	13	0.4
Dialysis	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Feeding Tube peg, NG DopHoff	6	0.3	0	0.0	0	0.0	5	0.5	0	0.0	11	0.4
Skin/Wound Care	4	0.2	0	0.0	0	0.0	1	0.1	0	0.0	5	0.2
Suction	1	0.1	0	0.0	0	0.0	3	0.3	0	0.0	4	0.1
Other	4	0.2	1	0.6	0	0.0	4	0.4	0	0.0	9	0.3
EQUIPMENT	131	7.5 %	5	3.2 %	9	6.7 %	81	7.7 %	1	3.3 %	227	7.3 %
IV pump	21	1.2	1	0.6	1	0.7	13	1.2	0	0.0	36	1.1
PCA pump	83	4.7	3	1.9	7	5.2	61	5.8	0	0.0	154	4.9
Implantable pump	1	0.1	0	0.0	0	0.0	0	0.0	0	0.0	1	0.0
Feeding pump	3	0.2	0	0.0	0	0.0	1	0.1	0	0.0	4	0.1
Pump service/maint	1	0.1	0	0.0	0	0.0	0	0.0	0	0.0	1	0.0
Ventilator	2	0.1	0	0.0	0	0.0	0	0.0	0	0.0	2	0.1
Bed	1	0.1	0	0.0	1	0.7	2	0.2	0	0.0	4	0.1
Rental	0	0.0	0	0.0	0	0.0	1	0.1	1	3.3	2	0.1
Other	19	1.1	1	0.6	0	0.0	3	0.3	0	0.0	23	0.7

Source: Project HOPE computations based on HCIS survey data.

_1 Column percents calculated as percent of total interventions

TABLE 5-14d: Frequency and Percent of Procedures and Visits by Source of Payment When Interventions Provided

	Medicare Hospice		Medicare Home Health		Medicaid		All Other		Missing		Total	
	#	%	#	%	#	%	#	%	#	%	#	%
TOTAL INTERVENTIONS	1,758		154		135		1,054		30		3,131	
TOTAL PROCEDURES/VISITS _1	345	19.6 %	42	27.3 %	22	16.3 %	118	11.2 %	6	20.0 %	501	16.0
SURGERY	46	2.6 %	3	1.9 %	4	3.0 %	8	0.8	1	3.3 %	30	1.0
Bowel Obstruction	5	0.3	2	1.3	0	0.0	1	0.1	1	3.3	9	0.3
Hip reduction/fracture	6	0.3	0	0.0	2	1.5	1	0.1	0	0.0	9	0.3
Tracheostomy	1	0.1	0	0.0	0	0.0	1	0.1	0	0.0	2	0.1
Lumbar puncture	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Biopsy	1	0.1	0	0.0	0	0.0	2	0.2	0	0.0	3	0.1
Placement of:												
Broviac, Hickman epidural or central catheter-subolavian or jugular	6	0.3	3	1.9	2	1.5	4	0.4	1	3.3	16	0.5
Gastrostomy, jejunostomy	6	0.3	1	0.6	1	0.7	1	0.1	0	0.0	9	0.3
DopHoff, nasogastric	0	0.0	0	0.0	1	0.7	0	0.0	0	0.0	1	0.0
Intraspinal catheter	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Implantable infusion pump	2	0.1	0	0.0	0	0.0	0	0.0	1	3.3	3	0.1
Other surgical procedure	19	1.1	4	2.6	2	1.5	12	1.1	2	6.7	39	1.2
RADIOLOGY	73	4.2 %	4	2.6 %	6	4.4 %	12	1.1 %	0	0.0 %	95	3.0
X-ray	14	0.8	0	0.0	4	3.0	3	0.3	0	0.0	21	0.7
Bone scan	11	0.6	2	1.3	0	0.0	5	0.5	0	0.0	18	0.6
Magnetic Resonance Imaging	5	0.3	0	0.0	0	0.0	0	0.0	0	0.0	5	0.2
Venogram	1	0.1	0	0.0	0	0.0	0	0.0	0	0.0	1	0.0
Computerized Tomography	33	1.9	2	1.3	2	1.5	2	0.2	0	0.0	39	1.2
Ultrasound	4	0.2	0	0.0	0	0.0	1	0.1	0	0.0	5	0.2
Other radiological procedure	5	0.3	0	0.0	0	0.0	1	0.1	0	0.0	6	0.2

TABLE 5-14d (continued): Frequency and Percent of Procedures and Visits by Source of Payment When Interventions Provide

	Medicare Hospice		Medicare Home Health		Medicaid		All Other		Missing		Total	
	#	%	#	%	#	%	#	%	#	%	#	%
CARDIOVASCULAR	1	0.1 %	0	0.0 %	0	0.0 %	3	0.3 %	0	0.0 %	4	0.1
Doppler testing	0	0.0	0	0.0	0	0.0	1	0.1	0	0.0	1	0.0
Echocardiogram	1	0.1	0	0.0	0	0.0	0	0.0	0	0.0	1	0.0
Electrocardiogram	0	0.0	0	0.0	0	0.0	1	0.1	0	0.0	1	0.0
Cardiopulmonary resuscitation	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Other cardiovascular procedure	0	0.0	0	0.0	0	0.0	1	0.1	0	0.0	1	0.0
RESPIRATORY	7	0.4 %	2	1.3 %	0	0.0 %	8	0.8 %	0	0.0 %	17	0.5
Bronchoscopy	0	0.0	0	0.0	0	0.0	1	0.1	0	0.0	1	0.0
Thoracenteais	4	0.2	2	1.3	0	0.0	2	0.2	0	0.0	8	0.3
Chest tube insertion	0	0.0	0	0.0	0	0.0	1	0.1	0	0.0	1	0.0
Intubation	0	0.0	0	0.0	0	0.0	1	0.1	0	0.0	1	0.0
Other respiratory procedure	3	0.2	0	0.0	0	0.0	3	0.3	0	0.0	6	0.2
GASTROINTESTINAL	9	0.5 %	3	1.9 %	0	0.0 %	5	0.5 %	0	0.0 %	17	0.5
Upper GI	0	0.0	0	0.0	0	0.0	1	0.1	0	0.0	1	0.0
Barium Enema	0	0.0	1	0.6	0	0.0	0	0.0	0	0.0	1	0.0
Paracenteais	3	0.2	2	1.3	0	0.0	3	0.3	0	0.0	8	0.3
Endoscopy	3	0.2	0	0.0	0	0.0	0	0.0	0	0.0	3	0.1
Other GI procedure	3	0.2	0	0.0	0	0.0	1	0.1	0	0.0	4	0.1
URINARY	6	0.3 %	2	1.3 %	0	0.0 %	1	0.1 %	0	0.0 %	9	0.3
Dialysis	3	0.2	1	0.6	0	0.0	1	0.1	0	0.0	5	0.2
Other urological procedure	3	0.2	1	0.6	0	0.0	0	0.0	0	0.0	4	0.1

TABLE 5-14d (continued): Frequency and Percent of Procedures and Visits by Source of Payment When Interventions Provide

	Medicare Hospice		Medicare Home Health		Medicaid		All Other		Missing		Total	
	#	%	#	%	#	%	#	%	#	%	#	%
NURSING	22	1.3 %	0	0.0 %	2	1.5 %	22	2.1 %	0	0.0 %	46	1.5
Nursing non-continuous visit	11	0.6	0	0.0	1	0.7	13	1.2	0	0.0	25	0.8
Nursing continuous care	11	0.6	0	0.0	1	0.7	9	0.9	0	0.0	21	0.7
PHYSICIAN	7	0.4 %	0	0.0 %	1	0.7 %	0	0.0 %	0	0.0 %	8	0.3
Visit	0	0.0	0	0.0	1	0.7	0	0.0	0	0.0	1	0.0
Exam	2	0.1	0	0.0	0	0.0	0	0.0	0	0.0	2	0.1
Consult	5	0.3	0	0.0	0	0.0	0	0.0	0	0.0	5	0.2
THERAPY	48	2.7 %	0	0.0 %	2	1.5 %	11	1.0 %	0	0.0 %	61	1.9
Physical Therapy	2	0.1	0	0.0	0	0.0	1	0.1	0	0.0	3	0.1
Occupational Therapy	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Respiratory/O2 Therapy	42	2.4	0	0.0	2	1.5	10	0.9	0	0.0	54	1.7
Social Work	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Pastoral	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Respite Care	4	0.2	0	0.0	0	0.0	0	0.0	0	0.0	4	0.1
LABORATORY	16	0.9 %	9	5.8 %	1	0.7 %	4	0.4 %	0	0.0 %	30	1.0
Blood culture	1	0.1	0	0.0	0	0.0	0	0.0	0	0.0	1	0.0
Urinalysis	2	0.1	0	0.0	0	0.0	0	0.0	0	0.0	2	0.1
Complete blood profile	1	0.1	7	4.5	0	0.0	2	0.2	0	0.0	10	0.3
Electrolyte screen-7 panel	0	0.0	1	0.6	0	0.0	0	0.0	0	0.0	1	0.0
Electrolyte screen-12 panel	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Prothrombin time	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Cytology	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Digoxin	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Dilantin	1	0.1	0	0.0	0	0.0	0	0.0	0	0.0	1	0.0
Theophylline	1	0.1	0	0.0	0	0.0	0	0.0	0	0.0	1	0.0
Wound Culture	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Other lab procedure	10	0.6	1	0.6	1	0.7	2	0.2	0	0.0	14	0.4

TABLE 5-14d (continued): Frequency and Percent of Procedures and Visits by Source of Payment When Interventions Provide

	Medicare Hospice		Medicare Home Health		Medicaid		All Other		Missing		Total	
	#	%	#	%	#	%	#	%	#	%	#	%
OTHER	110	6.3 %	19	12.3 %	6	4.4 %	44	4.2 %	5	16.7 %	184	5.9
ECG	0	0.0	0	0.0	0	0.0	1	0.1	0	0.0	1	0.0
Transportation	3	0.2	0	0.0	1	0.7	10	0.9	0	0.0	14	0.4
Emergency Room visit	0	0.0	0	0.0	0	0.0	2	0.2	0	0.0	2	0.1
Hospitalization	102	5.8	17	11.0	4	3.0	26	2.5	5	16.7	154	4.9
Other type of intervention	5	0.3	2	1.3	1	0.7	5	0.5	0	0.0	13	0.4

Source: Project HOPE computations based on HCIS survey data.

NOTE: The total number of interventions on Table 14 is higher than the total number of interventions noted on other tabl
Table 14 includes the combination interventions.

TABLE 5-15: Number and Percent of Type of and Select Specific Interventions Identified as High Cost, by Diagnosis

	DIAGNOSIS													
	Digestive Cancer		Respiratory Cancer		All Other Cancer		Immune System Disorders/ HIV Infection		All Other Non-Cancer		All Cancer		All Non-Cancer	
TOTAL CASES	323		302		742		13		208		1,367		221	
AVERAGE LENGTH OF STAY	84		78		92		103		98					
	#	%	#	%	#	%	#	%	#	%	#	%	#	%
TOTAL INTERVENTIONS	704	100.0	608	100.0	1,280	100.0	176	100.0	232	100.0	2,592	100.0	408	100.0
NARCOTICS	153	21.7	105	17.3	228	17.8	16	9.1	31	13.4	486	18.8	47	11.5
Morphine	79	11.2	65	10.7	130	10.2	8	4.5	27	11.6	274	10.6	35	8.6
Dilaudid	33	4.7	21	3.5	44	3.4	6	3.4	1	0.4	98	3.8	7	1.7
CHEMOTHERAPY	41	5.8	34	5.6	94	7.3	3	1.7	7	3.0	169	6.5	10	2.5
GENERAL MEDICATIONS	79	11.2	61	10.0	119	9.3	62	35.2	23	9.9	259	10.0	85	20.8
AZT	0	0.0	0	0.0	0	0.0	19	10.8	2	0.9	0	0.0	21	5.1
Pentamidine	0	0.0	0	0.0	0	0.0	20	11.4	0	0.0	0	0.0	20	4.9
Valium	27	3.8	40	6.6	62	4.8	8	4.5	5	2.2	129	5.0	13	3.2
Haldol	10	1.4	2	0.3	2	0.2	0	0.0	1	0.4	14	0.5	1	0.2
Comazine	5	0.7	2	0.3	9	0.7	1	0.6	0	0.0	16	0.6	1	0.2
Lasix	2	0.3	0	0.0	4	0.3	5	2.8	1	0.4	6	0.2	6	1.5
RADIATION THERAPY	31	4.4	77	12.7	114	8.9	1	0.6	7	3.0	222	8.6	8	2.0
HYPERALIMENTATION	12	1.7	0	0.0	10	0.8	4	2.3	5	2.2	22	0.8	9	2.2
BLOOD THERAPY	27	3.8	16	2.6	78	6.1	9	5.1	20	8.6	121	4.7	29	7.1
SUPPLIES	64	9.1	68	11.2	112	8.8	11	6.3	16	6.9	341	13.2	39	9.6
Intravenous	57	8.1	63	10.4	92	7.2	10	5.7	13	5.6	212	8.2	23	5.6
Respiratory	1	0.1	3	0.5	7	0.5	0	0.0	1	0.4	11	0.4	1	0.2

TABLE 5-15 (continued): Number and Percent of Type of and Select Specific Interventions Identified as High Cost, by Diagnosis

TOTAL CASES AVERAGE LENGTH OF STAY	DIAGNOSIS Digestive Cancer		Respiratory Cancer		All Other Cancer		Immune System Disorders/ HIV Infection		All Other Non-Cancer		All Cancer		All Non-Cancer	
	#	%	#	%	#	%	#	%	#	%	#	%	#	%
EQUIPMENT	57	8.1	34	5.6	55	4.3	3	1.7	20	8.6	130	5.3	23	5.6
Intravenous Pump	5	0.7	0	0.0	7	0.5	0	0.0	0	0.0	12	0.5	0	0.0
PCA Pump	46	6.5	26	4.3	39	3.0	2	1.1	12	5.2	111	4.3	14	3.4
PROCEDURE/VISITS	40	5.7	52	8.6	124	9.7	13	7.4	25	10.8	216	8.3	38	9.3
X-Ray	4	0.6	2	0.3	11	0.9	1	0.6	1	0.4	17	0.7	2	0.5
Bone Scan	1	0.1	6	1.0	9	0.7	0	0.0	0	0.0	16	0.6	0	0.0
CT Scan	5	0.7	15	2.5	18	1.4	2	1.1	5	2.2	38	1.5	7	1.7
Placement of: Broviac,	6	0.9	4	0.7	6	0.5	0	0.0	1	0.4	16	0.6	1	0.2
Hickman, epidural, or		0.0		0.0		0.0		0.0		0.0		0.0		0.0
central line		0.0		0.0		0.0		0.0		0.0		0.0		0.0
ER Visit	9	1.3	3	0.5	5	0.4	0	0.0	1	0.4	17	0.7	1	0.2
ENTERAL NUTRITION	13	1.8	5	0.8	17	1.3	0	0.0	7	3.0	35	1.4	7	1.7
HYDRATION THERAPY	48	6.8	37	6.1	76	5.9	17	9.7	18	7.8	161	6.2	35	8.6
THERAPY VISIT	7	1.0	20	3.3	28	2.2	5	2.8	7	3.0	55	2.1	12	2.9
PHYSICIAN VISIT	6	0.9	7	1.2	18	1.4	0	0.0	5	2.2	31	1.2	5	1.2
NURSING VISIT	17	2.4	1	0.2	27	2.1	2	1.1	8	3.4	45	1.7	10	2.5
HOSPITAL	33	4.7	48	7.9	55	4.3	6	3.4	12	5.2	136	5.2	18	4.4

TABLE 5-15 (continued): Number and Percent of Type of and Select Specific Interventions Identified as High Cost, by Diagnosis

TOTAL CASES AVERAGE LENGTH OF STAY	DIAGNOSIS Digestive Cancer		Respiratory Cancer		All Other Cancer		Immune System Disorders/ HIV Infection		All Other Non-Cancer		All Cancer		All Non-Cancer	
	#	%	#	%	#	%	#	%	#	%	#	%	#	%
ANTIBIOTICS	14	2.0	19	3.1	40	3.1	15	8.5	8	3.4	73	2.8	23	5.6
Kinacef	11	1.6	4	0.7	3	0.2	2	1.1	1	0.4	18	0.7	3	0.7
OTHER	62	8.8	24	3.9	85	6.6	9	5.1	13	5.6	171	6.6	22	5.4

Source: Project HOPE computations based on HCIS survey data.

Note: Because only select specific interventions are listed, the number will not add to the total number for the type of intervention (major category). Percents are column percents calculated as a proportion of total interventions.

TABLE 5-16: Frequency and Percent of Interventions Identified as High Cost by Pain Level at Admission and when Interventions are Provided

	Pain Levels												
AT ADMISSION	No Pain	No Pain	No Pain	Mild/ Moderate	Mild/ Moderate	Mild/ Moderate	Strong/ Severe	Strong/ Severe	Strong/ Severe	
WHEN INTERVENTION PROVIDED	No Pain	Mild/ Moderate	Strong/ Severe	No Pain	Mild/ Moderate	Strong/ Severe	No Pain	Mild/ Moderate	Strong/ Severe	Total Row Inter.
NUMBER OF CASES	210	115	34	98	451	244	36	114	178	
INTERVENTIONS	# %	# %	# %	# %	# %	# %	# %	# %	# %	
NARCOTICS	26 5.7%	22 4.8%	11 2.4%	23 5.1%	125 27.5%	111 24.4%	13 2.9%	51 11.2%	72 15.9%	454
Morphine	7 2.6	11 4.1	8 3.0	20 7.5	63 23.7	77 28.9	6 2.3	30 11.3	44 16.5	266
Dilaudid	12 14.5	6 7.2	0 0.0	0 0.0	32 38.6	12 14.5	0 0.0	15 18.1	6 7.2	83
Phenobarb	0 0.0	0 0.0	1 33.3	0 0.0	1 33.3	0 0.0	0 0.0	1 33.3	0 0.0	3
Demoral	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	2 100.0	2
Other	0 0.0	0 0.0	2 25.0	0 0.0	0 0.0	2 25.0	0 0.0	1 12.5	3 37.5	8
CHEMOTHERAPY	29 15.9	20 11.0	3 1.6	5 2.7	65 35.7	15 8.2	3 1.6	21 11.5	21 11.5	182
ANTIBIOTICS	19 20.9	7 7.7	0 0.0	12 13.2	21 23.1	14 15.4	1 1.1	13 14.3	4 4.4	91
GENERAL MEDICATIONS	54 17.2	33 10.5	0 0.0	16 5.1	111 35.4	44 14.0	1 0.3	38 12.1	17 5.4	314
Valium	25 19.5	18 14.1	1 0.8	8 6.3	44 34.4	14 10.9	1 0.8	15 11.7	2 1.6	128
Haldol	0 0.0	1 12.5	0 0.0	0 0.0	7 87.5	0 0.0	0 0.0	0 0.0	0 0.0	8
Solumedrol	2 28.6	0 0.0	0 0.0	0 0.0	2 28.6	1 14.3	0 0.0	2 28.6	0 0.0	7
Solumedrol	1 33.3	0 0.0	0 0.0	0 0.0	1 33.3	0 0.0	0 0.0	1 33.3	0 0.0	3
Ativan	1 20.0	0 0.0	0 0.0	0 0.0	0 0.0	3 60.0	0 0.0	0 0.0	1 20.0	5
ENTERAL NUTRITION	9 22.5	5 12.5	0 0.0	9 22.5	12 30.0	2 5.0	0 0.0	2 5.0	1 2.5	40
HYPERALIMENTATION	4 13.3	2 6.7	0 0.0	1 3.3	8 26.7	7 23.3	0 0.0	3 10.0	5 16.7	30
HYDRATION THERAPY	38 21.1	17 9.4	1 0.6	20 11.1	53 29.4	20 11.1	2 1.1	15 8.3	14 7.8	180

TABLE 5-16 (continued): Frequency and Percent of Interventions Identified as High Cost by Pain Level at Admission and when Interventions are Provided

AT ADMISSION	No Pain	No Pain	No Pain	Mild/ Moderate	Mild/ Moderate	Mild/ Moderate	Strong/ Severe	Strong/ Severe	Strong/ Severe	Total Row Inter.
WHEN INTERVENTION PROVIDED	No Pain	Mild/ Moderate	Strong/ Severe	No Pain	Mild/ Moderate	Strong/ Severe	No Pain	Mild/ Moderate	Strong/ Severe	
INTERVENTIONS	# %	# %	# %	# %	# %	# %	# %	# %	# %	
BLOOD THERAPY	18 12.9	15 10.7	4 2.9	10 7.1	47 33.6	18 12.9	8 5.7	10 7.1	10 7.1	140
SUPPLIES	48 20.1	33 13.8	1 0.4	17 7.1	81 33.9	13 5.4	4 1.7	33 13.8	9 3.8	239
EQUIPMENT	12 7.9	7 4.6	3 2.0	10 6.6	21 13.9	45 29.8	5 3.3	8 5.3	40 26.5	151
PCA Pumps	5 4.4	2 1.8	3 2.6	9 7.9	9 7.9	40 35.1	4 3.5	6 5.3	36 31.6	114
RADIATION THERAPY	20 9.8	15 7.3	4 2.0	6 2.9	70 34.1	33 16.1	9 4.4	18 8.8	30 14.6	205
PROCEDURES	33 14.5	21 9.2	7 3.1	6 2.6	78 34.2	37 16.2	1 0.4	18 7.9	27 11.8	228
NURSING	10 19.2	5 9.6	1 1.9	2 3.8	15 28.8	10 19.2	0 0.0	2 3.8	7 13.5	52
THERAPIST VISIT	8 13.8	2 3.4	0 0.0	4 6.9	22 37.9	9 15.5	2 3.4	7 12.1	4 6.9	58
Respirstory	7 14.0	1 2.0	0 0.0	1 2.0	20 40.0	9 18.0	1 2.0	7 14.0	4 8.0	50
OT/PT	0 0.0	0 0.0	0 0.0	0 0.0	1 50.0	0 0.0	1 50.0	0 0.0	0 0.0	2
PHYSICIAN VISITS	4 11.8	2 5.9	0 0.0	4 11.8	9 26.5	7 20.6	0 0.0	4 11.8	4 11.8	34
OTHER	9 6.4	11 7.9	3 2.1	9 6.4	57 40.7	17 12.1	2 1.4	17 12.1	15 10.7	140

SOURCE: Project HOPE computations based on NHO survey data for hospices responding to HCIS survey.

TABLE 5-17: Percent (Number) of Medicare Cases Identified as High Cost with Varying Proportions of Days Spent in General Inpatient Care by Type of Intervention and Select Specific Interventions

TYPE OF AND SPECIFIC INTERVENTIONS	Proportion of Total Days Spent In General Inpatient Care						
	No Inpatient Days	1-5%	6-10%	11-20%	21-49%	50-99%	Only Inpatient Days
Total Cases _1	548	114	75	88	86	29	25
NARCOTICS	23.2 %	8.8 %	14.7 %	15.9 %	24.4 %	16.7 %	16.0 %
	(127)	(10)	(10)	(14)	(21)	(3)	(4)
Morphine	53.2	46.2	58.8	7.1	60.0	20.0	42.9
	(92)	(6)	(10)	(1)	(12)	(1)	(3)
Dilaudid	0.6	7.7	0.0	21.4	10.0	0.0	0.0
	(1)	(1)	(0)	(3)	(2)	(0)	(0)
CHEMOTHERAPY	5.8	8.8	6.7	2.3	4.7	0.0	0.0
	(32)	(10)	(5)	(2)	(4)	(0)	(0)
ANTIBIOTICS	1.6	1.8	4.0	2.3	3.5	16.7	16.0
	(9)	(2)	(3)	(2)	(3)	(3)	(4)
GENERAL MEDICATIONS	3.5	4.4	8.0	6.8	9.3	5.6	12.0
	(19)	(5)	(6)	(6)	(8)	(1)	(3)
Valium	2.8	13.3	19.1	26.3	16.7	16.7	22.2
	(5)	(2)	(4)	(5)	(4)	(1)	(2)
RADIATION	11.1	7.0	8.0	11.4	12.8	14.7	8.0
	(61)	(8)	(6)	(10)	(11)	(2)	(2)

TABLE 5-17 (continued): Percent (Number of Medicare Cases Identified as High Cost With Varying Proportions of Days Spent in General Inpatient Care by Type of Intervention and Select Specific Interventions

TYPE OF AND SPECIFIC INTERVENTIONS	Proportion of Total Days Spent In General Inpatient Care						
	No Inpatient Days	1-5%	6-10%	11-20%	21-49%	50-99%	Only Inpatient Days
TPN	0.4	0.0	0.0	1.1	0.0	0.0	0.0
	(2)	(0)	(0)	(1)	(0)	(0)	(0)
BLOOD THERAPY	2.7	14.9	4.0	9.1	2.3	14.7	4.0
	(15)	(17)	(3)	(8)	(2)	(2)	(1)
SUPPLIES	10.0	2.6	1.3	5.7	4.7	29.3	8.0
	(55)	(3)	(1)	(5)	(4)	(4)	(2)
Supplies, IV	1.7	7.7	0.0	7.1	20.0	73.3	14.3
	(3)	(1)	(0)	(1)	(4)	(3)	(1)
SPECIFIC INTERVENTIONS							
EQUIPMENT	12.2	3.5	1.3	9.1	1.2	9.1	8.0
	(67)	(4)	(1)	(8)	(1)	(1)	(2)
PCA Pump	9.7	7.7	5.9	5.7	0.0	33.3	28.6
	(53)	(1)	(1)	(5)	(0)	(1)	(2)
PROCEDURE	5.3	9.7	12.0	5.7	8.1	11.1	4.0
	(29)	(11)	(9)	(5)	(7)	(2)	(1)
X-ray	2.3	0.0	0.0	7.1	0.0	0.0	0.0
	(4)	(0)	(0)	(1)	(0)	(0)	(0)
Bone Scan	1.7	7.7	0.0	0.0	0.0	0.0	0.0
	(3)	(1)	(0)	(0)	(0)	(0)	(0)

TABLE 5-17 (continued): Percent (Number of Medicare Cases Identified as High Cost With Varying Proportions of Days Spent in General Inpatient Care by Type of Intervention and Select Specific Interventions

TYPE OF AND SPECIFIC INTERVENTIONS	Proportion of Total Days Spent In General Inpatient Care						
	No Inpatient Days	1-5%	6-10%	11-20%	21-49%	50-99%	Only Inpatient Days
NURSING	1.2	0.0	1.3	0.0	1.2	0.0	0.0
	(7)	(0)	(1)	(0)	(1)	(0)	(0)
ENTERAL NUTRITION	2.6	0.9	1.3	0.0	0.0	0.0	0.0
	(14)	(1)	(1)	(0)	(0)	(0)	(0)
HYDRATION THERAPY	5.3	5.3	9.3	10.2	3.5	44.0	16.0
	(29)	(6)	(7)	(9)	(3)	(6)	(4)
OTHER THERAPY _2	2.7	1.7	0.0	1.1	2.3	0.0	4.0
	(15)	(2)	(0)	(1)	(2)	(0)	(1)
PHYSICIAN VISIT, EXAM, OR CONSULT	1.1	2.6	5.3	0.0	2.3	9.1	0.0
	(6)	(3)	(4)	(0)	(2)	(1)	(0)
COMBINATION	8.0	9.7	5.3	6.8	8.1	18.2	4.0
	(44)	(11)	(4)	(6)	(7)	(2)	(1)
OTHER _3	3.1	16.7	0.2	14.8	9.3	20.2	0.0
	(17)	(19)	(15)	(13)	(8)	(3)	(1)

Source: Project HOPE computations based on HCIS survey data.

_1 Percents calculated as a percent of cases in each inpatient stay category.

_2 Other therapy includes Physical Therapy, Occupational Therapy, Respiratory Therapy, and Social Worker visits.

_3 Other interventions include respite care, transportation, and unspecified interventions.

TABLE 5-18: Selected per Case Characteristics by Source of Payment

SELECTED CHARACTERISTICS	Medicare Hospice #	Medicare Hospice %	Medicare Home Health #	Medicare Home Health %	Medicaid #	Medicaid %	All Other #	All Other %
SEX								
Male	528	53.3%	48	48.0%	41	51.3%	270	55.2%
Female	428	43.2	52	52.0	39	48.8	219	44.8
AGE								
65 plus	875	88.3%	83	83.0%	7	8.9%	102	21.0%
50-64	56	5.7	3	3.0	17	21.5	239	49.3
35-49	20	2.0	12	12.0	36	45.6	97	20.0
20-34	2	0.2	1	1.0	18	22.8	35	7.2
under 20	1	0.1	1	1.0	1	1.3	12	2.5
ETHNIC BACKGROUND								
White	896	90.4%	90	90.0%	59	71.1%	447	89.6%
Hispanic	13	1.3	5	5.0	8	9.6	8	1.6
Black	31	3.1	4	4.0	11	13.3	22	4.4
Other	34	3.4	1	1.0	5	6.0	22	4.4
LENGTH OF STAY (days)	88		89		110		63	
DIAGNOSIS								
Cancer	859	86.7%	58	81.7%	63	71.6%	385	88.9%
Non-Cancer	115	11.6	13	18.3	25	28.4	48	11.1
INTERVENTIONS PER CASE RATIO	1.73		2.14		1.74		2.15	

TABLE 5-18 (continued): Selected per Case Characteristics by Source of Payment

SELECTED CHARACTERISTICS	Medicare Hospice #	Medicare Hospice %	Medicare Home Health #	Medicare Home Health %	Medicaid #	Medicaid %	All Other #	All Other %
FREQUENCY OF ISTERVENTIONS PER CASE								
NARCOTICS	371	37.4 %	15	21.1 %	20	31.5 %	218	48.1
Morphine	220	22.2	12	16.9	15	16.9	112	24.7
Dilaudid	53	5.3	1	1.4	1	1.1	56	12.4
CHEMOTHERAPY	90	9.1	41	57.7	13	14.6	79	17.4
GENERAL MEDICATIONS	150	15.1	9	12.7	23	25.8	183	40.4
AZT	4	0.4	2	2.8	7	7.9	10	2.2
Pentamidine	0	0.0	1	1.4	13	14.6	9	2.0
Valium	60	6.1	2	2.8	0	0.0	77	17.0
Lasix	11	1.1	2	2.8	0	0.0	1	0.2
ANTIBIOTICS	75	7.6	3	4.2	0	0.0	22	4.9
RADIATION THERAPY	137	13.8	15	21.1	14	15.7	63	13.9
HYPERALIMENTATION	9	0.9	5	7.0	1	1.1	19	4.2
ENTERAL NUTRITION	27	2.7	2	2.8	5	5.6	11	2.4
HYDRATION THERAPY	129	13.0	9	12.7	9	10.1	63	13.9
BLOOD THERAPY	99	10.0	11	15.5	8	9.0	43	9.5

TABLE 5-18 (continued): Selected per Case Characteristics by Source of Payment

SELECTED CHARACTERISTICS	Medicare Hospice #	Medicare Hospice %	Medicare Home Health #	Medicare Home Health %	Medicaid #	Medicaid %	All Other #	All Other %
SUPPLIES	222	22.4	3	4.2	8	9.0	165	36.4
Intravenous	132	13.3	1	1.4	3	3.4	105	23.2
Dialysis	0	0.0	1	1.4	1	1.1	0	0.0
EQUIPMENT	131	13.2	5	7.0	9	10.1	81	17.9
IV Pump	21	2.1	0	0.0	1	1.1	13	2.9
PCA Pump	78	7.9	1	1.4	7	7.9	61	13.5
PROCEDURE/ VISITS	212	21.4	25	35.2	18	20.2	91	20.1
Bowel Obstruction Surgery	5	0.5	2	2.8	0	0.0	1	0.2
Hip Surgery	6	0.6	0	0.0	2	2.2	1	0.2
Placement of Central Line	6	0.6	3	4.2	2	2.2	4	0.9
CT Scan	33	3.3	2	2.8	2	2.2	2	0.4
X-ray	14	1.4	0	0.0	4	4.5	3	0.7
Bone Scan	11	1.1	2	2.8	0	0.0	5	1.1
Lab	16	1.6	9	12.7	1	1.1	4	0.9
Nursing Visit	22	2.2	0	0.0	2	2.2	22	4.9
Resp. Therapist	42	4.2	0	0.0	2	2.2	10	2.2

Source: Project HOPE computations based on HCIS survey data.

CHAPTER 6

PAYMENT POLICY IMPLICATIONS AND PAYMENT RECOMMENDATIONS

6.1 Background

Presently, Medicare pays the cost of all covered hospice care, including costs associated with high cost individuals and high cost care, through the Medicare hospice prospective payment rate system (based on reasonable costs) and through separate fee-for-service payments for hospice physician services. In response to industry concerns over the adverse financial consequences associated with particular instances of high cost hospice care, and the ability of hospices to effectively manage the risk associated with the provision of this care within the present hospice payment system, Congress enacted section 6016 of the OBRA 1989. This statute directed the Secretary of Health and Human Services to conduct this study of high cost hospice care provided to Medicare beneficiaries. Implicit was the need to gather data necessary to develop methods and make recommendations to compensate hospices for providing such care.

After initially evaluating the OBRA 1989 legislation, it became apparent that HCFA did not possess the data to make an evaluation of the high cost problem or to prepare this report along with the necessary recommendations. To accomplish this task, patient level data on specific services rendered to individual Medicare hospice patients were needed. Because of the prospective features inherent in the Medicare hospice payment rate system, Medicare does not routinely collect data on specific services rendered to specific hospice patients or on specific hospice patient diagnoses through either the Medicare hospice cost reporting or the Medicare hospice billing systems. Thus, to be responsive to Congress, an external data collection effort, culminating in this report, was necessary to secure data needed to make an evaluation of the extent of the high-cost problem and to provide data needed to make recommendations for a solution. HCFA undertook this research effort in an attempt to determine the characteristics, cost, and frequency of high cost hospice care.

There has been much speculation as to what should be considered to be true hospice high cost outliers. As indicated in Chapter 3, a list of broadly defined interventions considered to be high cost was tentatively identified. This list was further refined based on hospice survey results (see Chapter 5), and a list of 12 broad categories (types of interventions) was developed. Specific interventions identified by hospices participating in the survey were then assigned to these broad categories. Unfortunately, total cost information on the specific interventions provided within these broad categories remains elusive despite the extensive research effort. In addition, the research indicated an extremely low frequency of occurrence for many of the identified interventions. There were only nine types of interventions identified where each intervention accounted for

more than 5 percent of all interventions provided.

6.2 Identified Payment Approaches

Several approaches were initially considered in the examination of alternatives to develop methods to compensate hospice programs for high cost hospice care. Approaches that were initially considered included:

a. Establishment of a dollar threshold amount per beneficiary that, when exceeded, would trigger an outlier payment. This approach would in essence be an exception process under which Medicare would pay some portion or all costs of beneficiary care in excess of a stipulated dollar threshold amount upon petition by the hospice. Measurement of dollars expended per beneficiary would reflect either the reasonable cost of services provided to the beneficiary, or the hospice's reasonable charges for the services. Two alternatives considered under this general approach included:

- o An exception process whereby HCFA would make additional (outlier) payment(s) at 100 percent of reasonable cost or charge for patient incurred expenses above a predetermined dollar threshold amount (or possibly a variable dollar threshold amount based on hospice length of stay).

- o An exception process whereby HCFA would make additional (outlier) payment(s) at some stipulated percentage (less than 100 percent) of reasonable cost or charge for patient incurred expenses above a predetermined dollar threshold amount (or possibly a variable dollar threshold amount based on hospice length of stay).

b. Identification of specifically identifiable therapies for which outlier payment(s) would be made. This approach would have provided an outlier payment(s) upon documentation that a particular therapy was necessary and furnished by the hospice. Two alternatives considered under this general approach included:

- o Additional lump-sum payment(s) for the documented occurrence of a particular therapy.

- o Additional per diem payment(s) for the documented per diem occurrence of a particular therapy.

c. Identification of specific conditions or patient diagnoses that would trigger outlier payment(s). Two alternatives considered under this general approach included:

- o Additional lump-sum payment(s) for the documented existence of a particular condition or diagnosis.
- o Additional per diem payment(s) for the documented existence of a particular condition or diagnosis.

d. Continuation of the current Medicare hospice payment system, which includes payment for high cost services within the prospectively determined hospice payment rates.

6.3 Payment Approach Issues

Some of the issues requiring consideration when evaluating the initial methodological approaches included: the administrative feasibility of the various approaches and the potential for payment system abuse for each of the payment approaches; and, an evaluation of the methodological approach in terms of its initial and continuing budget impact.

a. Administrative Feasibility and Potential for System Abuse. Each of the initial methodological approaches has strengths and weaknesses, requires different initial and ongoing data sets, and presents unique design problems to control possible trust fund abuse.

1. Establishment of a Dollar Threshold Amount. Unfortunately, the current billing system for Medicare hospice care precludes an outlier payment approach similar to that used in making outlier payments under Medicare's prospective payment system for hospitals. The key facet missing in the hospice billing system is the absence of charge or cost data on particular services provided to individual patients. The absence of a requirement to maintain a uniform charge structure or of requirements to submit charge data for each service provided to a Medicare beneficiary illustrates the simplicity of the hospice billing and cost reporting/auditing systems, which HCFA and hospices view as one of the most significant advantages of the hospice prospective payment system over cost-based reimbursement. To alter this system of information exchange would be very burdensome to hospices and HCFA and would seriously undermine the current prospective payment system.

Unlike the hospice payment system, Medicare routinely collects beneficiary charge and cost data on hospital services furnished to Medicare beneficiaries. This collection of beneficiary-specific charge and cost data is historically grounded in the old reasonable cost hospital reimbursement system, and remains an integral part of the current Medicare hospital cost reporting and auditing system. The very existence of this complex system enables the operation of the Medicare hospital outlier payment system.

The lack of charge data on particular services furnished to individual hospice patients makes outlier payment approaches based on individual patient dollar amounts problematic in terms of accountability and potential for payment system abuse. A system relying upon collection of individual beneficiary cost information rather than charge data would be problematic as well since it would be impractical to attempt to collect and even harder to verify individual beneficiary cost data.

However, a payment system approach based on dollars expended on individual patients (either charge or cost) does have certain advantages over the other approaches. The major advantage of the dollar threshold approach is that it has the flexibility to accommodate an infinite range of ever changing high-cost therapies. In addition, such a system could be designed with inherent utilization controls (similar to coinsurance) by setting a payment percentage at a value less than 100 percent. Such an approach would greatly reduce the financial risk to hospices of adverse selection while retaining incentives to reduce costs by limiting utilization of health services. To do this, however, hospice cost finding and cost reporting procedures would need to be completely revamped to permit cost data to be captured.

2. Identification of Specifically Identifiable Therapies. Linking outlier payment to the existence of a particular therapy was also problematic. The literature review, while helpful in describing state of the art pain control techniques, provided very little cost information for the variety of technologies and treatments discussed. Where cost information were provided, typically only purchase costs were mentioned. The cost of additional staff time or other costs associated with certain intervention procedures was not available. Thus, there is little information known on the total costs associated with a given technology or procedure.

Setting aside for the moment the possible bias in the survey data on interventions, the data were deficient from a cost collection standpoint in that self-definition of interventions yielded inconsistent information across respondent hospices. Various measurements were also not clearly defined

in the survey process, yielding inconsistent measurement information across respondent hospices. In short, the cost information collected through the survey was not useful in establishing payment amounts for specifically identifiable therapies or groups of therapies.

The survey did provide information for over 3,000 interventions. Interventions were assigned both a broad category (type of intervention) and a more specific category (specific intervention). While some of the therapies or interventions identified in the data, such as the use of a morphine pumps or renal dialysis services, would seem to be relatively stable in terms of cost, other therapies such as the use of antibiotics and palliative radiation therapy are not. Thus, even if acceptable cost information were available, pricing of specific interventions would have been very difficult and cumbersome. Attaching price tags to the broadly defined categories would similarly have proven very difficult. In addition, linking outlier payments to a particular therapy may present difficulties from a program integrity view, as the threshold occurrence triggering the payment or the medical necessity of the occurrence, may not always be easily determined.

One general observation on the categorical intervention pricing approach is that such an approach is not as flexible as the dollar threshold approach. This study has shown that an enormous variety of interventions, including both high tech and high cost interventions, exist in the rapidly changing field of effective pain control techniques. This environment for high cost technologies can only be described as dynamic. Thus, a categorical intervention pricing approach would have required continuing adjustments and additions to technologies or therapies qualifying for outlier payment status.

3. Identification of Specific Conditions or Diagnoses. Linking outlier payment to the existence of a particular diagnosis was not feasible. Although the current hospice billing system could most likely be modified to include coding for patient diagnosis, what hospices identified as high-cost cases do not appear to be related to individual patient diagnosis. The research data show that the distribution of diagnoses across cases and across interventions are similar. Thus it does not appear to be possible to identify or distinguish high cost cases based on diagnosis alone.

4. Continuation of the Current Medicare Hospice Payment System. This approach seems the most feasible administratively and seems to provide the most protection against payment system abuse. The budget impact of continuation of the present system would, of course, be neutral.

Individual hospices concerned with the financial impact of an occasional high cost patient could explore the availability of reinsurance through the private sector. Reinsurance, if available, would serve to reduce the financial impact of an occasional high cost patient. If such policies are not presently available to individual hospices, major hospice industry groups may wish to explore the feasibility of this alternative with private sector insurance carriers. Reinsurance may be especially desirable for small hospice programs to cover extraordinary patient costs.

In the Health Maintenance Organization (HMO) industry, such insurance is routinely purchased through private insurance carriers. Typically, the reinsurance policy protects against the risk of loss due to an occasional high cost patient by reimbursing the HMO for its expenditures (or some percentage thereof) above a stipulated amount after a deductible is met. If it is determined that reinsurance can be made available to hospices and that such costs are necessary, consideration of an adjustment to the hospice payment rates to include a cost factor for this expense may be warranted.

b. Budget Neutrality.

1. Medicare Hospice Budget Neutrality. An overriding issue of great concern to HCFA during its evaluation of the methodological approaches to compensate hospice programs for high cost hospice care was whether or not the outlier payment system was to be budget neutral. Considering the recent increases to the hospice rates (20 percent in FY 1990 and 5.2 percent in FY 1991) and the apparent health of the hospice industry, strong consideration was given to the development and ultimate recommendation of an approach that would have a neutral impact on the budget.

The most straightforward approach to a budget-neutral design of a hospice outlier payment system would reduce individual hospice per diem rate(s) in order to fund the outlier payments.

2. Medicare Part A and Part B Budget Neutrality. Another approach has also been suggested and considered. Under this approach, payments for high cost hospice outliers need not be budget neutral in the sense that funding for the outlier payments must come from reductions in the hospice per diem payment amounts. This alternative is founded on the proposition that since Medicare is already expending Medicare Part A and Part B dollars under the regular Medicare program for terminally ill beneficiaries who shift in and out of the hospice benefit to receive some

curative services not normally covered under the benefit in addition to palliative services, Medicare could simply redirect these funds so that care and payment for these services could be channeled through the hospice. Ostensibly, patient "switching" occurs in order to maximize payments and to use regular Medicare acute care coverage, especially where high-cost procedures are necessary and covered under the regular Medicare program.

We examined the assumptions that underlie this approach by measuring total Medicare expenditures for patients electing hospice care. Our examination showed that, in 1988, over 73 percent of total Medicare expenditures for patients electing hospice care were hospice care expenditures. Conversely, less than 27 percent of total Medicare expenditures on hospice care patients were regular Medicare Part A and Part B expenditures, many of which, as noted below, would continue under this proposed approach. These figures seem to reduce the dimension of the basis for the proposition in that they indicate Medicare is not spending large amounts under the regular Medicare program for hospice patients seeking curative care services for conditions unrelated to the terminal condition, in addition to palliative hospice care.

This position is further buttressed by other factors contributing to regular Medicare expenditures on beneficiaries electing the hospice benefit. There are several explanations for regular Medicare Part A and Part B expenditures other than the patient's desire to receive curative services not normally covered under the benefit (such as surgery or radiation therapy) in addition to palliative services. These factors include:

- payment for attending physician services, which are not waived services, are not considered hospice care expenditures, and are included in regular Medicare expenditures;

- payment for services unrelated to the terminal illness, which are not waived services, are not hospice care services, and are included in regular Medicare expenditures; and,

- payment for services provided after the 210 day hospice benefit limit was reached, which are included in regular Medicare program expenditures. (As OBRA 1990 removed this 210 day benefit limit, we expect these expenditures to decline).

Although it is not always possible to infer from the data the intent behind changes in coverage from palliative to curative care, it appears that a large portion of regular Medicare Part A and Part B expenditures for patients electing hospice care are attributable to the above factors. In addition, other factors such as the patient going into remission or a change in patient residence, may further account for regular Medicare Part A and Part B expenditures. Unfortunately, it is not possible to determine exact proportions of regular Medicare expenditures attributable to each of these factors. However, it appears that the portion of nonhospice regular Medicare Part A and Part B expenditures attributable to patient selection of curative services augmenting palliative care services is very small. Consequently, HCFA has focused its examination of the budget impact of an outlier payment system on adjustments to the current hospice rates.

Several approaches were explored by HCFA to achieve the desired goal of budget neutrality. Each approach contemplates an offset to the current hospice prospective payment rates by an estimated factor actuarially equivalent to total outlier payments. Of course, the difficulty in achieving budget neutrality under any approach lies in estimating the incidence of outlier occurrences and in developing an equitable adjustment to the present hospice prospective payment rates to fund the outlier payment system. Equally important are future adjustments to the rates to assure ongoing budget neutrality and an adequate pool of money to fund the outlier system. An approach linking outlier utilization on a continuing basis with future adjustments to the hospice payment rates would serve as a utilization control over the incidence of use of outlier services.

Several options were considered to adjust the prospectively determined hospice payment rates in order to achieve budget neutrality. One approach would involve making payment rate adjustments at the national level, linked to total hospice outlier expenditures. Another approach would involve making payment rate adjustments at the hospice level, linked to individual hospice outlier expenditures. Finally, hospice payment rate adjustments to achieve budget neutrality could involve some combination of these two approaches.

Making payment rate adjustments at the national level would avoid further complication of the hospice prospective payment system and would have been simpler to carry out administratively. Adjusting the payment rates at the hospice level by linking individual hospice utilization to the payment rate adjustment appears more equitable to individual hospices and could have been based on a retrospective look at the hospice's outlier

utilization during the previous year with payment rate adjustments made in the next year. However, this approach may have been difficult to administer and would likely have resulted in payment errors.

c. **Issues Concerning Identification of High Cost Interventions.**

1. Observations on the CAP Meeting. While the CAP was helpful in terms of understanding more about state-of-the-art type procedures currently in use to palliate and manage terminal illnesses, the panel conceded it was not equipped to provide specifics on overall frequencies of specific procedures or their costs. Some issues raised by the panel, such as the perceived hospice access problem, may be important contemporary issues facing hospices but may be beyond the scope of consideration when contemplating payment system modifications only. Other points raised by the panelists, including payment system modifications focusing on "last resort-only" high cost procedures and an overall evaluation of the impact of modifications to the payment structure, are particularly well taken and appropriate in evaluating whether modifications should be made to the current Medicare hospice payment system.

The panel did develop a list of medications, modes of administration, and types of procedures which it believed can lead to high costs. This list is detailed in Chapter 4. Unfortunately, this list is very broad. More specifics are needed before HCFA can contemplate alterations to the current payment system to accommodate payment modifications for specific outlier procedures which may fall within these broad categories. Operational prospective payment systems cannot be modified to permit such a broad spectrum of outlier program payments without clearer delineation as to what is paid through the system and what is paid outside the system. Lack of clarity can and almost certainly will create opportunities for program abuse. Some hospice providers may attempt to maximize revenues in a manner similar to "DRG creep" in the Medicare PPS system. In the much more unstructured hospice context, this result would necessitate costly claims review not now necessary under the hospice payment system. The detection and control of inappropriate billings and program payments can be extremely difficult to accomplish in such situations.

With regard to the panel's broad categories of high cost procedures, we believe more consideration needs to be given as to how interventions within these categories are paid under the current payment system. While each item mentioned by the panel undoubtedly can be costly, we believe

the financial risks associated with the occasional provision of these services, where appropriate, can be managed within the present hospice payment system.

One intervention named by the clinical panel was palliative radiation therapy. Palliative radiation therapy costs were an integral part of the "outpatient therapies" component of the initial prospective payment rates established by HCFA. These initial prospective payment rates are the foundation upon which legislative increases to the current hospice payment rates have been, and continue to be, based. Palliative radiation therapy provided during the course of an inpatient hospice stay is paid through the general inpatient care rate of $354.73, which encompasses payment for inpatient routine operating costs and ancillary services such as radiation therapy. Palliative radiation therapy provided on an outpatient basis is paid through the routine home care rate of $79.74, which encompasses payment for outpatient therapies including radiation and chemotherapy. In addition, any physician services provided by the hospice in connection with palliative radiation therapy were reimbursed to the hospice at 100 percent of the reasonable charge for the service. However, since January, 1992, all physician payments have been made based on the Medicare fee schedule.

We believe the financial risk associated with the relatively rare occurrence of a patient needing palliative radiation therapy is overstated, and is certainly limited only to the nonphysician costs of the therapy. For example, in the case of an outpatient palliative radiation procedure, estimated by one panel member at $3,000 (which we will assume includes no physician costs), one could estimate that hospice billings for 581 routine home care days, achieved through service to roughly 13 patients, would establish a fund sufficient to pay for the procedure.[1] Certainly, even relatively small hospices, with an average monthly census of 15 patients, should be able to manage this degree of risk.

Another intervention named by the clinical panel was surgery. Assuming most high cost surgeries are done on an inpatient basis,

[1]We base this estimate on the portion of the hospice routine home care rate attributable to outpatient therapies ($5.16 per day currently, after updating for legislative increases), the percentage of hospice days billed as routine home care (approximately 96 percent in 1989), and an average length of stay of around 46 days in 1989.

hospices are paid for these costs through the general inpatient care rate and through separate payment to the hospice for physician services. Over 20 percent of the initial general inpatient care rate represented a cost component for ancillary service costs. While this percentage may appear to be low in relation to the percentage of ancillary costs in a typical hospital day in the acute care setting, it is consistent with the hospice philosophy of care, and reflected actual average daily costs of ancillary services provided to hospice patients during the Medicare hospice demonstration, including ancillary costs associated with necessary palliative surgical procedures. In addition to these payments, hospice physician services associated with the performance of the surgical procedure are paid to the hospice at 100 percent of the Medicare reasonable charges, resulting in no risk to the hospice for physician costs associated with surgery. Thus, it appears to us that hospices should be able to manage the risks associated with occasional surgical procedures necessary for the palliation and management of the terminal illness, within the current prospective payment system.

The clinical panel also suggested modifications to the hospice payment structure. We considered these recommendations in developing our initial approaches to designing alterations to the hospice payment system, discussed earlier.

Finally, the clinical panel proposed a research agenda to address the lack of data on the costs and use of interventions considered to be high cost. Endorsement of this agenda may have been appropriate if we believed there was a need to further study the hospice high cost problem; however, we believe there is little evidence to show that an outlier payment system for high cost cases/procedures is truly needed. Moreover, we believe the disadvantages to both hospices and HCFA associated with ultimate implementation of such a system far outweigh the potential advantages to be gained.

2. Observations on High Cost Intervention Study. As indicated in chapter 5, there is reason to believe that the survey results may potentially be biased. However, we believe the payment policy implications based on what was learned from the surveys is not affected by the potential sampling bias. In the survey, hospices reported information on services which they considered to be high cost. Because the survey represented, in effect, a "first cut" on the types of interventions which might potentially be considered high cost, clear definitions on what interventions were to be considered high cost and guidelines on measuring the frequency and cost of such interventions were not provided. The usefulness of the survey

results was, accordingly, limited. Cost and measurement information on most interventions was not usable. However, the survey results were useful in other respects.

Responding hospices identified over 10 percent of their total case load as high cost. From a payment policy perspective, such a surprisingly high figure raises questions as to whether these cases represent true "outliers." When data on total hospice length of stay is overlaid on cases considered by hospices to be high cost, it was found that the average length of stay for these patients is nearly twice the average. It appears that hospices may have identified long-stay patients rather than true cost outliers. These patients may not necessarily have higher per diem costs. Medicare payments to the hospice for these long stay patients is proportionately higher, since payment is on a per diem basis. In effect, Medicare is already paying hospices higher overall amounts for cases hospices identify as high cost.

The survey analysis identified few interventions as occurring frequently across the broad spectrum of hospice care. Narcotics and their administration were the most frequently mentioned, however the cost and administration of these drugs is included in the per diem rates. Little evidence is available to show that the costs associated with administration of narcotics is truly an outlier.

The route of administration of the narcotic drug may be a better indicator of potential overall costs. For example, use of an IV pump may indicate a higher cost of intervention than other means of administration, due to the additional costs incurred not only for the pump but also for more intensive nursing and other support services. However, further research would be needed to show the extent of use of alternatives to oral delivery. In addition, research would be needed to establish that these incurred costs are truly atypical vis-a-vis the current hospice payment rates and, thus, should be paid through an outlier system.

3. Medicare Coverage of Identified Interventions. Although it is necessary to point out the inadequacies of available cost data, it is more important to examine high cost hospice care in light of the traditional goals and purposes of the Medicare hospice benefit. Since the inception of the benefit, Medicare has covered only those services that are "reasonable and necessary for the palliation and management of the terminal illness." This policy is specifically mandated by section 1862(a) of the Social Security Act. Care which is curative in nature is not covered under the hospice program, although coverage for curative care is available outside of the hospice benefit if the beneficiary chooses to

revoke his or her election of the hospice benefit. When the hospice benefit was implemented, the distinction between curative and palliative care was more easily drawn. In some cases, chemotherapy or radiation services generally considered to be "curative" are appropriately used to alleviate pain and discomfort. However, as medical technology advances, it appears that the lines between curative and palliative care are becoming blurred, and hospices must make difficult decisions about treatment.

When data becomes available that can isolate specific treatments or procedures as exceptionally high cost, it will be important that this care is scrutinized to determine whether it can be characterized as either mainly curative or mainly palliative in nature. Before making decisions about including additional payment for these services, we must determine if the care is appropriate for management of the illness or easing pain, rather than combating the illness or prolonging the patient's life. Similarly, if we should choose to institute an outlier system predicated on the cost of care for a particular patient, we must be able to ascertain that the care furnished to that patient is truly palliative.

The distinction between curative and palliative care, although increasingly difficult to draw, is the very foundation of the Medicare hospice benefit. The benefit has traditionally been perceived as a means of providing coordinated and personal care, primarily in the home, to the dying patient who has chosen to seek this care as an alternative to the curative care available under the Medicare program generally. The statutory provision requiring the patient to waive one set of services in exchange for hospice care is a key attribute of the program. There has always been an offshoot of the hospice movement whose members favor palliative care in addition to curative care with the objective of using hospice not as a substitute for but as an addition to curative care. We must keep these original goals in mind to ensure that any outlier system that is considered continues the traditional and statutory focus of hospice on palliative care.

6.4 Summary

The lack of objective, reliable, and comprehensive data has rendered consideration of a revision to Medicare hospice coverage policy to allow for special high cost outlier coverage nearly impossible. Similarly, the form and quality of data collected in the research effort has eliminated from consideration the recommendation of any approaches initially considered to compensate hospice programs for high cost hospice care. As we have seen, available data analyses have not been able to isolate any specific high cost treatments, therapies, or illnesses as being true outliers to the current rates which also are found to occur with relative frequency across the spectrum of

hospice care. It is this data that would be used to form the foundation of a coverage and payment policy for outlier services.

More important, we believe the data collected through this research effort weigh against a decision to make any modification to the current prospective payment system for hospice care. Accordingly, we believe that no further consideration need be given to additional data collection efforts supporting development of an outlier payment system.

To date, data have been either anecdotal in nature, such as the information gleaned from the meeting of the hospice clinical panel, or inconsistently gathered from only a small percentage of the hospice provider population, as was the case with the survey results. Information of this nature, although useful as background material, is not a sufficient base to consider modification of Medicare policy to allow payment for outliers. In fact, much of the anecdotal information which asserts that Medicare payment is inadequate for hospice care is plainly contradicted by the strong growth experienced by the benefit in recent years. This is borne out by the tremendous growth rate in the number of Medicare certified hospices, as indicated in Chapter 3. Data evidencing this tremendous growth in Medicare hospice care contradicts the view that insufficient or inconsistent payment is driving hospice providers away from participation in the Medicare program. Similarly, not a single Medicare hospice has exceeded the annual payment cap. Coupled with the fact that most hospice providers serve small numbers of patients, this seems to show that very high cost treatment stays have not become common throughout even a single hospice's patient census.

It is also necessary to point out that none of the information gathered from either the survey data or the panel of clinical experts suggests that patients are not receiving needed high cost services. Instead, the information shows that these services are being furnished by both hospice and nonhospice Medicare providers. All evidence shows that these patients are, in fact, receiving needed services (albeit sometimes these services are outside the scope of the Medicare hospice benefit). The Medicare statute was explicitly constructed recognizing this delineation of Medicare systems for coverage and payment of hospice services as an alternative mode of health service delivery. The continuation of the delineation of these systems governing coverage and payment for alternative modes of health service delivery may be desirable.

Also, evidence suggests that many of the varied services identified as high cost by hospices are furnished to only a minimal percentage of terminal patients. In addition, some hospices have indicated that they do not provide many of the services mentioned because delivery of such services is inconsistent with their hospice philosophy of care. When one considers this information, it appears that the benefits to be gained by altering the hospice benefit to allow for increased payment to hospices for services that are already covered in other areas of the Medicare program may not justify the

resulting complications and disturbance to a coverage and payment system that is otherwise simple and effective. In short, we must guard against complicating the current system, which has worked extremely well for most providers, in a manner which could ultimately benefit only a few providers. This consideration is particularly important if it is decided that any expenditures for high cost services must be offset by a reduction in the routine or other payment rates.

6.5 Recommendation

We recommend continuation of the current Medicare hospice payment system, which includes payment for high cost services within the prospectively determined hospice payment rates, to compensate hospice programs for providing high cost hospice care to Medicare beneficiaries.

CHAPTER 7

SUMMARY AND CONCLUSIONS

7.1 Purpose

This study set out to: 1) clarify the meaning of high cost hospice care, 2) identify which Medicare hospice services are high cost; 3) determine or estimate the average cost of these services; 4) ascertain the dimensions of use of high cost services; and 5) identify the characteristics of patients receiving high cost hospice care. Four sources of information were used to provide background information on these issues: 1) a brief literature review; 2) HCFA administrative data on hospice use and expenditures; 3) deliberations of a clinical advisory panel; and 4) hospice patient data from a survey of hospices.

Although much of what we learned from these sources is useful, there is no indication that hospices are being financially threatened by occasional more expensive patients. In particular, it appears that the incidence of true cost outliers is very rare. Many of the patients identified by hospices as high cost were long stay patients. Evidence from the HCFA reimbursement files suggest that long stay patients are actually less expensive to treat per day of life than shorter stay patients. Major modification of the current system of hospice reimbursement under Medicare is unwarranted at this time, especially given the recent payment rate increase.

7.2 What Are High Cost Hospice Services and How Much Do They Cost?

Part of the charge to HCFA was to evaluate the ability of hospices to provide high cost forms of care. However, a clear definition of which types of services or interventions are high cost does not exist. From the information and data gathered for this report, there seem to be two ways to approach defining high cost hospice care:

- o intervention level--identifying specific treatments, interventions, or procedures that are themselves costly to provide; or

- o patient level--identifying types of patients that tend to require more intense service (either in terms of increased nursing visits, increased supervision by a hospice provider, or use of more sophisticated technologies that may be higher in cost than more traditional technologies).

The goal of the literature review was to identify state-of-the-art hospice care and pain control technologies, thus, this source provided background information relevant to the intervention-level approach. Most of the articles focused on pain control technologies.

This is not surprising, given that pain relief is a major goal of hospice care and that pain is a symptom frequently experienced by terminally ill cancer patients.

However, with the exception of two articles that mention the costs associated with certain types of interventions, very little information on costs was available from this source. Although these articles typically mentioned the purchase costs associated with specific technologies, they generally did not attempt to estimate the other types of costs associated with providing these interventions.

Several characteristics of these technologies that might lead to high costs were mentioned, however. Use of these interventions may be associated with the need for highly skilled personnel to initiate the use of a particular intervention, extra nursing visits, increased patient monitoring, treatment of various side effects (e.g., infections due to catheter placement), and the need to clean and maintain equipment (e.g., cleaning and refilling a morphine pump). Not one article or study mentioned the costs of performing these services. In addition, none of the articles discussed whether the costs associated with a particular technology might differ by the setting in which it was used. Thus, there is no information comparing the costs of providing these interventions or technologies in hospices versus providing them in traditional acute care settings.

Both the literature review articles and the CAP deliberations suggested that the newer, more sophisticated technologies may be more efficient and appropriate forms of pain control. There was little evidence to support this claim; however, as no studies have been conducted to evaluate the costs and outcomes of these interventions across different settings, or in comparison to traditional forms of pain control. Also, although there are claims that certain technologies, such as implantable drug delivery systems, are less costly in the long run since they may lead to reduced need for other types of pain interventions, there was little hard evidence to support this belief. In short, despite anecdotal support for use of these interventions, there is not enough evidence to conclude definitively that the more sophisticated interventions are better, even if they may cost less in the long run.

The CAP identified types of interventions that are likely to be high cost. Their list included many of the technologies identified by the literature review as state-of-the-art (e.g., implantable drug delivery pumps) as well as other types of interventions (surgery, radiation therapy, and certain drugs). However, the panel was unable to attach cost estimates to the interventions they identified. As was indicated by the literature review, they cited a lack of well-documented evidence on the total costs associated with providing these interventions. The panelists emphasized the need for additional research into the costs of these interventions.

The panel members also attempted to define high costs through the second, patient-level approach. While they discussed certain segments of the population as likely to be high cost (e.g., the indigent and potential patients who are unlikely to receive hospice care

because they lack a primary caregiver or appropriate home situation), they also attempted to identify patient characteristics that would lead to high costs. The panelists decided that it was very difficult to discuss the concept of the average patient versus a high cost patient based on potential, patient-level indicators of high cost care (e.g., a diagnosis of AIDS or presenting with difficult-to-manage pain). As corroborated by the literature review, defining an average patient is difficult because pain is a very subjective experience and intensity of pain is difficult to measure. In addition, types of symptoms associated with particular diagnoses (e.g., AIDS) are frequently not specific only to that particular diagnosis, thus, patients with a diagnosis other than the one specified may not be considered high cost. If during the course of their stay in the hospice they require high cost forms of care, however, they still may be a financial liability for the hospice provider.

Evidence on which interventions or patients are high cost from our third source--the NHO's survey data--may be misleading because respondents were allowed to self-define high cost cases. This is a problem because, for example, smaller hospices may differ from larger hospices in which types of interventions or patients result in high costs. While both small and large hospices report what they consider to be high cost, they are not likely to be reporting on the same set of interventions. It is unclear whether providers responding to the survey set out to gather information on the patients that they considered to be high cost (due to the total cost of their care over the entire length of their stay) or on the interventions that they considered to be high cost, regardless of whether the patients receiving these interventions were high cost patients overall. Since so few cases received the interventions identified as high cost, hospices appear to have identified patients considered to be high cost cases because of unusually long lengths of stay and large absolute costs, not the outlier cases. In addition, the reported cost data could not be interpreted due to lack of consistent definition. While some interventions were mentioned frequently (e.g., certain types of pump drug delivery systems), it is clear that there is not a consensus among hospice providers on what is considered to be high cost care, either at the patient-level or the intervention-level.

Of note is the low frequency of occurrence for any of the identified interventions. Even for the broader type of intervention categories, only nine types of interventions accounted for more than 5 percent of all the interventions provided. For specific interventions, those occurring with high frequency accounted for over 1 percent of all interventions. Thus, hospice providers seem to be reporting on a broader sample of patients than just the outlier cases with very high costs. In fact, there is some evidence that many of these cases are high cost in an aggregate, overall sense due to unusually long lengths of stay rather than being high cost because atypically costly interventions were provided to these patients.

Also, despite the original list of nine interventions identified as high cost, only use of morphine pumps also was fairly frequently mentioned in the survey. None of the

respondent hospices identified dialysis as a high cost intervention, and the use of TPN and antibiotics was rarely identified as a high cost intervention.

7.3 What Are the Dimensions of Use Associated with These High Cost Interventions?

While there are few, if any, studies examining differential use of care and pain control technologies in hospice settings compared to other settings, there is some evidence that the more sophisticated high tech interventions are more frequently provided in hospital settings or cancer research centers than they are in hospices. Most of the literature review and CAP deliberations focused on the concept of "appropriate" use rather than characterizing different dimensions of use in different settings.

There was some consensus in the literature that a logical approach to pain control existed, although adequate pain control remains a major challenge. Pharmacologic management of pain was identified as the most common, followed by more interventional types of care such as surgery. It was clear that surgical procedures are viewed as a last resort, and only performed after careful consideration. This was borne out by the panel deliberations, in which the panelists suggested that surgery was likely to be used with discretion even if additional reimbursement were available. The survey data revealed almost no use of the surgical interventions identified by the CAP for the relief of pain (i.e., hip surgery and bowel obstruction). Most of the surgical procedures involved tube placement.

There are several controversies associated with pharmacologic management, however. Much of the literature focused on a step-by-step approach to drug use and pain control. Patients with mild pain should be treated with an NSAID or other nonopioid, perhaps in conjunction with an adjuvant analgesic. Higher intensity pain should be treated with opioid-nonopioid combinations or "weak" opioids, followed by opioids such as morphine for severe pain. However, choice of analgesic and the appropriate route and schedule of administration are controversial issues. Despite evidence from the literature review and CAP members that oral administration is considered the safest and frequently the most economical, more sophisticated modes of intravenous delivery have become popular.

The clinical panel members were concerned that patients are receiving more sophisticated types of pain control than they really need to control pain adequately. Examining the survey data shows that most of the patients identified as high cost (or those receiving interventions identified as high cost) were those experiencing no pain or mild-moderate pain throughout most of their stay in a hospice program. A smaller percentage of the patients in the sample were experiencing strong-severe pain, and very few were experiencing intractable pain. However, given the limitations of the data, these results should not be construed as a definitive example of patients receiving unnecessary care.

Dimensions of use associated with types of care other than pain control consist mainly of the use of hyperalimentation (or TPN). The literature review revealed that for terminally ill cancer patients, hyperalimentation may do more harm than good. Several panel members suggested that use of TPN was highly controversial, and neither hyperalimentation nor TPN were frequently mentioned in the survey data.

7.4 What Are the Characteristics of Patients Receiving These Types of Care?

Most of the information on the characteristics of patients receiving these types of care comes from the survey. Although demographic information suggests that the patients identified as high cost are not likely to differ greatly from the average hospice patient, high cost patients may experience longer lengths of stay than the average hospice patient.

7.5 Conclusion

In conclusion, there are several points to be made regarding the usefulness of this information for modifying the current reimbursement system for hospices under Medicare:

- Neither the literature review, the CAP deliberations, nor the survey data provided enough information to identify precisely which types of patients are always high cost or which interventions are always high cost. Indeed, there is little understanding of whether services are costly relative to other services, relative to Medicare per diem payment rates, or relative to the particular situation in which they are used.

- While there is general agreement as to which approaches to pain control are appropriate, and some concern about inappropriate use of the newer high tech forms of care (especially in the hospice setting), there is a lack of consensus on what constitutes appropriate care and how these newer technologies fit into this scheme. There is even a division among hospice providers as to whether the more sophisticated technologies are necessary for providing hospice care.

- There is a dearth of data to support the industry claim that provision of interventions identified as high cost is creating financial liability.
- The Medicare hospice benefit has grown rapidly in terms of the number of certified hospice providers, the subsequent number of Medicare beneficiaries who elect the benefit, and the resultant increase in Medicare overall hospice expenditures. The number of certified hospice providers has more than tripled from 317 at the end of 1986, the first year of the permanent benefit, to 995 by mid-1991.

- In the 1987 to 1989 period, freestanding and home health based hospices accounted for 42 percent and 38 percent of patients, respectively. However, hospital based hospices are the fastest growing type of provider.

- In 1989, 2 percent of hospices served 18 percent of all Medicare hospice patients. At the other end of the size spectrum, 31 percent of hospices had fewer than 25 Medicare patients in 1989. However, rapid growth in the 1987 to 1989 time period suggests that the smallest hospices are relatively new and will increase patient case-load in subsequent years. In addition, size of hospice, calculated from Medicare enrollment, tends to overestimate financial vulnerability because non-Medicare enrollees expand the reimbursement base.

- The average per capita Part A and Part B expenditures for all 47,000 hospice enrollees under study during 1987-88 was $63.71.

- Total Medicare hospice expenditures increased from $92 million in 1987 to $171 million in 1988. In addition, there were Part A and Part B expenditures for hospice enrollees of $43 million in 1987 and $62 million in 1988. Total Medicare expenditures per hospice enrollee were $4,641 in 1987 and $4,931 in 1988, a 6 percent increase. Payments for hospice services accounted for 68 percent of Medicare expenditures for hospice enrollees in 1987 and 73 percent in 1988.

- The 66,584 enrollees in 1989 represent a 33 percent increase over 1988.

- An estimated 20 percent of Medicare beneficiaries dying of cancer in 1989 used hospice, varying considerably by State.

- Length of hospice stay increased rapidly in the 1987 to 1989 time period. Overall length of stay increased from 38.5 days to 47.9 days, a 24 percent increase. In 1989, the Medicare Catastrophic Coverage Act (MCCA) was in effect and the 210 day limit to the hospice benefit was removed. The 210 day limit was reinstated with the revocation of MCCA (1990); and removed again in 1991.

- There was almost no change in total Medicare expenditures from 1987 to 1988 for persons whose posthospice enrollment life span was less than 90 days. Average Part A hospice expenditures were about $2,000 and additional Part A and Part B expenditures were about $600 in both years. These shorter lived persons averaged $85.40 total Part A and Part B expenditures, including hospice, per day from date of election of hospice to date of death in 1987; $83.75 per day of life from hospice election to death in 1988.

- For persons whose life span was greater than 90 days, hospice Part A expenditures increased by about $2,100 per person, but additional Part A and Part B expenditures decreased by about $900 per person, resulting in a net increase in total Medicare expenditures from $12,584 per Medicare hospice enrollee in 1987 to $13,817 in 1988. These longer lived persons averaged $41.08 total Part A and Part B expenditures, including hospice, per day from date of election of hospice to date of death in 1987; $50.66 per day of life from hospice election to death in 1988.

- Persons who have gaps in their hospice enrollment and/or terminate hospice enrollment before dying are the most expensive in terms of their total Medicare expenditures, because of the length of life. These persons account for 15 percent of all patients, 29 percent of all hospice payments, and 59 percent of all Part A and Part B expenditures among hospice enrollees. However, on a per diem basis, they are the least expensive hospice patients, with an average $46.54 per diem reimbursement for all Part A and Part B. This is considerably lower than the Medicare hospice routine home care payment rate of $63.17 in FY 1987-89.

- In FY 1991 the routine home care rate was raised to $79.94 and the Medicare general hospital inpatient payment rate was raised to $354.73.

- Several approaches were initially considered in the examination of alternatives to develop methods to compensate hospice programs for high cost hospice care. Approaches initially considered to pay for high cost hospice care included:

  1. Establishment of a dollar threshold amount per beneficiary, which when exceeded would trigger outlier payment. (The lack of charge data on particular services furnished to individual hospice patients makes outlier payment approaches based on individual patient dollar amounts problematic in terms of accountability and potential for payment system abuse.)

  2. Identification of specifically identifiable therapies to trigger outlier payment; (Linking outlier payment to the existence of a particular therapy is problematic in that there is little information known on the total costs associated with a given technology or procedure. Even if acceptable cost information was available, pricing of specific interventions or categories of interventions would have been very difficult and cumbersome. Linking outlier payments to a particular therapy may also present difficulties from a program integrity view.)

  3. Identification of specific conditions or patient diagnosis, which would trigger outlier payment; and, (Linking outlier payment to the existence of a particular diagnosis was not feasible. Although the current hospice billing system could most likely be modified to include coding for patient diagnosis, what hospices identified as high cost cases do not appear to be related to individual patient diagnosis.)

  4. Continuation of the current Medicare hospice payment system, which includes payment for high cost services within the prospectively determined hospice payment rates. (Continuation seems to provide the most protection against payment system abuse. The budget impact of continuation of the present system would, of course, be neutral, and individual hospices concerned with the

financial impact of an occasional high cost patient could explore the availability of reinsurance through the private sector.)

- Considering the recent increases to the hospice rates (20 percent in FY 1990 and 5.2 percent in FY 1991) and the apparent health of the hospice industry, strong consideration was given to the development and ultimate recommendation of an approach that would have a neutral impact on the budget. If an outlier payment system were adopted, the best approach to achieve budget neutrality appears to be some form of reduction in the current hospice payment rates.

- In the intervention study, hospices identified over 10 percent of their total case load as high cost. From a payment policy perspective, such a surprisingly high figure raises questions as to whether these cases represent true outliers. It appears as though hospices may have identified long-stay patients rather than true cost outliers. Since Medicare payment is on a per diem basis, Medicare is already paying hospices higher overall amounts for cases hospices identify as high cost.

- Little evidence is available to show that the cost associated with each particular identified intervention is truly an outlier. Research would be needed to establish that these incurred costs are truly atypical vis-a-vis the current hospice payment rates, and thus should be paid through an outlier system.

- It is important to examine high cost hospice care in light of the traditional goals and purposes of the Medicare hospice benefit. The benefit has traditionally been perceived as a means of providing coordinated and personal palliative care, primarily in the home, to the dying patient who has chosen to seek this care as an alternative to the curative care available under the Medicare program generally. It is important that specific high cost treatments or procedures be scrutinized to determine whether they are mainly curative or mainly palliative in nature. We must determine if the care is appropriate for management of the illness or easing pain, rather than combating the illness or prolonging the patient's life. There has always been an offshoot of the hospice movement whose members favor palliative care in addition to curative care with the objective of using hospice not as a substitute for but as an addition to curative care. We must continue to keep traditional hospice goals in mind to ensure that any outlier system that is considered continues the traditional and statutory focus of hospice on palliative care.

- With regard to the clinical panel's broad categories of high cost procedures, we believe more consideration needs to be given as to how interventions within these categories are paid under the current payment system. While each item mentioned by the panel undoubtedly can be costly, we believe the financial risks associated with the occasional provision of these services, where appropriate, can be managed within the present hospice payment system.

- The data collected through this study argue against the modification of the current prospective payment system to provide separate payment for high cost outlier cases. Anecdotal information that decries the alleged inadequacy of the Medicare payments for hospice care is plainly contradicted by the strong growth experienced by the benefit in recent years, the recent increase in reimbursement rates, and the relatively low per day Medicare expenditures for those longer lived patients who revoked the hospice benefit, lower than the Medicare basic home care rate.

When one considers this information, it appears that any benefits to be gained by altering the hospice reimbursement mechanism to allow for increased payment to hospices for services that are already covered in the per diem rates or in other areas of the Medicare program may not justify the resulting complications and disturbance to a coverage and payment system that is otherwise considered to be simple and effective.

7.6 Recommendation

We recommend continuation of the current Medicare hospice payment system, which includes payment for high cost services within the prospectively determined hospice payment rates, to compensate hospice programs for providing high cost hospice care to Medicare beneficiaries.

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APPENDIX A

Glossary of Terms

GLOSSARY OF TERMS

Adjuvant:	A substance added to a drug product formulation which affects the action of the active ingredient in a predictable way.
Agonist:	A drug capable of combining with receptors to initiate drug actions; it possesses affinity and intrinsic activity.
Analgesic:	Analgetic; a compound capable of producing analgesia; i.e., one that relieves pain by altering perception of nociceptive stimuli without producing anesthesia or loss of consciousness.
Anesthetic:	Anesthetic agent or compound that reversibly depresses neuronal function, producing loss of ability to perceive pain and/or other sensations.
Antagonist:	Denoting certain drugs that tend to neutralize or impede the action or effect of other drugs.
Bolus:	Large volume of fluid given intravenously and rapidly at one time for immediate response (e.g., a bolus injection of an analgesic could be provided to relieve sudden pain).
Carcinoma:	Any of the various types of malignant neoplasms derived from epithelial tissue in several sites.
Deafferentation:	A loss of the sensory nerve fibers from a portion of the body.
Dysesthesia:	1. Impairment of sensation short of anesthesia. 2. Condition in which a disagreeable sensation is produced by ordinary stimuli.
Epidural:	Peridural; upon or outside the dura mater (tough, fibrous membrane forming the outer envelope of the brain and spinal cord).
Iatrogenic:	Denoting an unfavorable response to therapy, induced by the therapeutic effort itself.
Intranasal:	Within the nasal cavity.
Intrathecal:	Within a sheath; ensheathed.

Intraventricular:	Within a ventricle of the brain or heart.
Mechanoreceptor:	Receptor which has the role of responding to mechanical pressures; e.g., receptors in the carotid sinuses, touch receptors in the skin.
Metastases:	In cancer, the appearance of neoplasms in parts of the body remote from the seat of the primary tumor; it results from dissemination of tumor cells by the lymphatic or blood vessels, or through serous cavities or subarachnoid or other spaces, and if widespread usually renders the cancer incurable by surgery alone.
Narcotic:	Any substance producing stupor associated with analgesia; specifically, a drug derived from opium or opium-like compounds, with potent analgesic effects associated with significant alteration of mood and behavior; and with the potential for dependence and tolerance following repeated administration (nonnarcotics do not cause tolerance or physical dependence).
Neurolytic/ Neurolysis:	1. Destruction of nerve tissue. 2. Freeing of a nerve from inflammatory adhesions.
Nociceptive:	Capable of appreciation or transmission of pain (a nociceptor is a peripheral nerve organ or mechanism for the appreciation and transmission of painful or injurious stimuli.
Opiate:	Any preparation or derivative of opium.
Opioids:	Synthetic narcotics that resemble opiates in action but are not derived from opium.
Palliative:	Mitigating; reducing the severity of, denoting the alleviation of symptoms without curing the underlying disease.
Parenteral:	By some other means than through the gastrointestinal tract; (i.v., intramuscular, etc.)
Pathophysiology:	Derangement of function seen in disease; alteration in function as distinguished from structural defects.
Sublingual:	Hypoglossal; below or beneath the tongue.

Tachyphylaxis:	Rapid appearance of progressive decrease in response following repetitive administration of a pharmacologically or physiologically active substance.

APPENDIX B

Annotated Bibliography

American College of Physicians, Position Paper. "Parenteral Nutrition in Patients Receiving Cancer Chemotherapy." Annals of Internal Medicine 110(9): pp 734-736; May 1, 1989.

This position paper addresses "the value of nutritional support for patients undergoing chemotherapy or combined chemotherapy and radiotherapy." Parenteral nutrition provides amounts of nutrients (e.g., glucose, amino acids, trace elements, vitamins) to patients whose tolerance for oral feeding has decreased or whose caloric intake is hard to maintain. The amount of each nutrient varies according to clinical situation and the nutrients are delivered through a central or peripheral venous access (bypassing regular digestion and absorption processes).

This paper pools the results of 12 randomized controlled trials to assess the efficacy, safety, and effectiveness of parenteral nutrition. The College recommendations state that "the evidence suggests that parenteral nutritional support was associated with net harm, and no conditions could be defined in which such treatment appeared to be of benefit." The College recommends that basic scientific investigation into the determinants of malnutrition in cancer patients and the effect of parenteral nutrition on the metabolism of these patients is essential.

Denobile, J. "Long-Term Epidural Pain Relief Using a Totally Implantable Access System," Journal of Surgical Oncology; 43 (1990).

The majority of cancer patients at the terminal stage experience pain as a major symptom, and less than 60 percent of patients receive adequate pain relief. Over the past 7 years, control of cancer-related pain through the use of narcotics infused via an epidural catheter has become increasingly popular. In this study, patients with a life expectancy of more than 6 weeks, and who had adequate pain relief from temporary catheter placement, eventually received an implanted system (tunneled catheter and injection port). After 24 hours of intermittent injection to determine daily morphine requirements, the patients were placed on a patient-controlled analgesia (PCA) system of continuous infusion plus on-demand bolus via an externally worn pump (Pharmacia Deltec, Inc., 5200)

Physicians followed patients in the hospital on a daily basis. When and if discharged, patients returned every 2 weeks for clinic visits. Home health nurses assisted patients at home, provided infusion pump cassette changes and instructed patient and family in self care.

With the epidural catheter, as opposed to high dose oral and IV opiates, patients required far less morphine to obtain 80-90 percent improvement in pain control. They also experienced fewer side effects. Catheter life span ranged from 15 days to 157 days. Not one patient chose to return to previous method of pain management. [Study does not mention sample size.]

Drexel, H. "Treatment of Severe Cancer Pain by Low-Dose Continuous Subcutaneous Morphine," Pain; 36 (1989).

This article describes a controlled clinical trial which compares the efficacy and safety of a continuous subcutaneous morphine infusion with conventional intermittent or subcutaneous morphine application for patients with severe chronic cancer pain. The study demonstrates that, compared to conventional therapy, continuous subcutaneous infusion produces better pain relief, fewer side effects and requires very low opioid doses. As assessed by nurses or patient relatives, quality of life was also significantly improved by continuous infusion.

The article also states that pain is a major symptom in about 70 percent of cancer patients and it is now widely accepted that cancer pain should be treated by the three-step use of nonopioid, weak opioid, and strong opioid analgesics.

Enck, RE. "Adjuvant Analgesic Drugs." The American Journal of Hospice Care, pp. 9-10; March/April 1989.

The article briefly reviews current uses of adjuvant analgesic drugs. These are drugs that are added to narcotic analgesics to improve cancer pain control by providing additive analgesia without increasing the narcotic dose. The author states that there is a lack of controlled studies providing data on the effectiveness of adjuvant analgesic drugs, and a diversity of opinion on the appropriate use of these agents. Although the author does not recommend routine use of many of these drugs, he provides six parameters for their effective use until further scientific evidence is available. These parameters indicate that some types of drugs, when used as adjuvant analgesics, are useful in certain clinical situations. Dosage levels for some drugs are still subject to debate.

Enck, R.E. "Transdermal Narcotics for Pain Control." The American Journal of Hospice and Palliative Care; pp. 15-17; July/August 1990.

Transdermal administration of drugs is not a new idea, and drugs such as nitroglycerin, clonidine, and scopolamine have been used with transdermal systems. One type of transdermal "patch" consists of an outer backing membrane, a drug reservoir containing the active drug, a specifically permeable membrane, and a pressure sensitive adhesive layer.

The "inclusion of a rate controlling membrane provides an opportunity to diminish fluctuations in drug levels, thereby reducing the potential for exposure to subtherapeutic or toxic serum concentrations." The noninvasive nature of this technology leads to a high degree of patient acceptability, less frequent administration increases patient compliance, and adverse effects are minimized (e.g., gastrointestinal problems related to oral dosing are eliminated).

The use of transdermal systems with fentanyl citrate, a synthetic narcotic analgesic that is approximately 75 times more potent than morphine, is appealing for use in hospice care. The author reviews four clinical studies of fentanyl patches and concludes that, given the particular system used in the studies, use of fentanyl administered through a transdermal system was shown to be safe and effective in a postoperative setting and is a promising technique for management of chronic cancer pain. As of the date of this article's publication, the system under study has not been approved by the Food and Drug Administration.

Fedder, S.L. "Intrathecal Administration of Morphine for Pain of Malignant Origin" Surgery, Gynecology and Obstetrics, 170:273-5; March 1990.

This article reviews the use and efficacy of continuous intrathecal administration of morphine for pain of malignant origin. As a palliative therapy, continuous intrathecal administration of morphine should be considered only for patients in whom all reversible causes of pain have been addressed, significant psychologic factors have been ruled out or treated, compression of the spinal cord is nonexistent, and life expectancy is at least greater than 30 days (preferably 3 months). While the advent of totally implantable drug-delivery systems and preservative-free morphine preparations represent tremendous advances, there is a lack of personnel familiar with the maintenance of these pumps and thus a limit to current use of the technology. Intrathecal systems are currently preferred to epidural continuous or intermittent systems because they have a lower complication rate. Continuous systems have some advantages over intermittent systems (e.g., stable levels of drugs and less frequent incidence of side effects such as respiratory depression and infection).

In 90 percent of the studies reviewed, a marked decrease or elimination of systemic narcotics was associated with an improved quality of life. The reviewer concludes that intrathecally administered morphine is a safe and effective method of providing analgesia and that most patients are then able to lead productive lives. Neuroablative procedures are typically either delayed or eliminated. Increased use of these systems is predicted as familiarity with them grows.

Ferrer-Brechner, T. "Anesthetic Management of Cancer Pain," Seminars in Oncology; 12:4 (December, 1985).

Anesthetic procedures, namely diagnostic and therapeutic nerve blocks, have been used to treat cancer pain for more than 50 years. For many years, anesthesiologists used neural blockade as the main modality for management of localized cancer-related pain. Anesthetic management of cancer pain involves the insertion of a needle close to a peripheral nerve, neural plexus, or nerve root to inject a solution that will give a temporary or prolonged neural blockade. Because the needle must be precisely placed, fluoroscopic procedures are necessary for certain blocks.

There are two types of neural blockades: a diagnostic nerve block and therapeutic nerve blocks. Diagnostic nerve blocks are done with reversible agents of known duration, such as local anesthetics. Therapeutic nerve blocks are performed with agents that are considered neurolytic, such as phenol, alcohol, and ammonium sulfate. These can last up to 6 months. In all cases, a diagnostic block with local anesthetic must be done prior to a therapeutic nerve block. Neurolytic blocks are high risk procedures and are therefore used as a last resort. In a previous study, the author found that only 25 percent of her clinic population required high-risk neuroblative or neuroaugmentative procedures.

Nerve blocking is only one of the many tools available for the management of cancer pain and should never be used as sole therapy at any time. A combination of anesthetic and nonanesthetic methods of cancer pain control is often more effective than the use of either one alone.

Foley, K. "The Treatment of Cancer Pain," New England Journal of Medicine; July 11, 1985.

The article discusses various types of pain associated with cancer and trends in methods for treating cancer-related pain. The author suggests that the most effective treatment for cancer patients is a multidisciplinary approach including analgesic drug therapy, neurosurgical and anesthetic procedures, behavioral methods, and supportive care. Exactly what combination of therapies is used is dependent on the patient, what type of pain the patient is experiencing, and the stage of the disease. Patients with cancer frequently have multiple causes of pain.

The most common cause of pain in patients with cancer is that associated directly with tumor involvement and the most common type of therapy is drug therapy using nonnarcotic, narcotic, and adjuvant analgesic drugs. Neurosurgical, anesthetic, and behavioral therapies are commonly used in conjunction with drug therapy. Neurosurgical and anesthetic approaches are being reassessed, particularly as they are most useful for managing localized pain before development of serious nerve injury.

"Changing attitudes toward the effective use of narcotic analgesics, the development of novel routes and methods of administration, and a clinical approach based on scientific principles and humane care offer the promise of improved management of pain in patients with cancer."

Gaylor, M.S.; and Coombs, DW. "New Technology: Morphine Pump." Psychiatric Medicine 5(3):219-234; 1987.

Comparing intraspinal techniques to conventional routes of narcotic administration (e.g., to a central line) reveals the potential advantages of these methods. Currently, heparin, FUDR (chemotherapeutic agent), and morphine are the only drugs approved for delivery through implantable systems. The clinical efficacy of intraspinal techniques has been implied by several reports: patients tend to require less oral narcotics, have a clearer sensorium, and appear to have fewer side effects. Although continuous intraspinal narcotic analgesia is a reversible alternative to neuroablative approaches, the health care team must be continuously involved, unlike other approaches. The device must be refilled which necessitates either an office or a home nurse visit.

Patients treated through an implanted pump (delivering narcotics intraspinally) appear to experience decreases in reported pain level, decreases in use of oral analgesics, and increases in the return to social and other pursuits.

Gustafson, L. "Spinal Opioid Analgesia: A Critical Update," Drugs; 35 (1988).

Intravenous (extrathecal) morphine administration is currently considered an established method of controlling postoperative and cancer-induced pain conditions. Several controlled clinical trials in postoperative patients have demonstrated that a single dose of morphine administered by the spinal route (intrathecal) gives a more long-lasting action than a similar IV dose. It is not known whether frequent patient-controlled administration of morphine may provide equally good analgesia without additional side effects. The use of spinal morphine in the treatment of cancer-related pain is based on limited clinical experience only.

Administration of various opioids by the spinal (intrathecal or extradural) route was introduced clinically in 1979. The number of controlled clinical studies evaluating the efficacy of intrathecal morphine administration in the postoperative period is limited. The authors are not aware of any well-designed study comparing the effect of single or repeated spinal doses (extradural or intrathecal) with frequent-dose administration of opioids by the intravenous route (e.g., with patient-controlled analgesic pumps). Thus, it is unknown whether frequent patient-controlled administration by the systemic route may provide equally effective analgesia without additional side effects.

The hourly dose of morphine has been suggested to be five times higher when given intravenously as compared to when given by the extradural route.

Kinzbrunner, B.M.; Policzer, J; Miller, B; and Neiber, L. "Noninvasive Pain Control in the Terminally Ill Patient," The American Journal of Hospice and Palliative Care; pp 26-29; July/August 1990.

Pain control for terminally ill patients remains a major challenge. Among cancer patients in the late stages of disease, 65 to 85 percent experience pain, which is frequently inadequately controlled as the patient's disease progresses. The authors, in response to perceived dearth of attention paid to less invasive routes of analgesic administration (in favor of newer, "high tech" therapies), review more traditional methods of pain control.

This article explores the effectiveness of oral, rectal, and sublingual therapy in controlling pain based on a study of 70 consecutive patients admitted to one hospice's inpatient facility. Patient level of pain and level of consciousness were evaluated by the registered nurse responsible for administering the patient's narcotic analgesic. Pain was measured on a scale of zero to three, and level of consciousness on a scale of zero to four. The results indicate, according to the authors, that around the clock, noninvasive administration of narcotic analgesics is effective in controlling pain in advanced terminally ill patients in a hospice inpatient setting. Despite demonstrated decrease in levels of pain, however, there was no significant change in patient level of consciousness.

Long, D. "Relief of Cancer Pain by Surgical and Nerve Blocking Procedures," JAMA, 244(24):2759-2761; December 19, 1980.

This article reviews surgical and percutaneous procedures used for treating cancer pain. The author states that destructive procedures should not be used in the early phases of cancer pain and that the risks of the interventional procedures may be too great for many patients. To undertake these procedures: 1) the cause of the pain should be clearly understood; 2) the pain should be serious enough to warrant drastic treatment; 3) the procedure used should be the most appropriate for the pain and for the expected longevity of the patient; and 4) the life span of the patient should be long enough to warrant the procedure. Procedures reviewed are hypophysectomy, cordotomy, midline myelotomy, sacral rhizotomy, cranial nerve section for relief of head and neck pain, cingulumotomy, intrathecal alcohol injection, nerve blocks, and neuroaugmentation. They are considered in light of types of cancer pain for which each procedure is most appropriate.

Lubenow, T. "Intraspinal Narcotics for Treatment of Cancer Pain," Seminars in Surgical Oncology; 6: pp 173-179 (1990).

The treatment of cancer pain through intraspinal narcotics is a relatively recent innovation and is indicated when pain is poorly controlled with high doses of systemic narcotics, or when patients experience limiting narcotic side effects. The advantages of epidural and subarachnoid over systemic narcotic administration are a longer duration of analgesia and lower effective dose. However, the administration of intraspinal narcotics is technically more difficult and requires skilled personnel.

To deliver intraspinal narcotics, a pump and catheter must be inserted either in the epidural or subarachnoid spaces. The placement of a fully implanted pump connected to a subarachnoid catheter is generally done by a neurosurgeon. Epidural catheter insertion is usually done by an anesthesiologist. The catheter is connected to a portable infusion pump which can be programmed by the physician for continuous infusion. There are several different models of infusion pumps. The most effective utilization of epidural narcotic infusions for the ambulatory patient is achieved with a portable pump. Important features in addition to portability and programming capability are the ability to deliver a continuous infusion plus intermittent self-dosing and the ease of use of the device by the patient.

Miller, R.J.; and Albright, PG. "What is the Role of Nutritional Support and Hydration in Terminal Cancer Patients?" The American Journal of Hospice and Palliative Care; pp. 33-38; November/December 1989.

Through a survey of 40 hospice nurses and 30 clinical nurses, and supplemented by data from several literature sources, the authors review the medical, legal, and ethical issues associated with nutritional support and hydration. According to one source, malnutrition is present in 80 percent of terminal patients. Although there are strong symbolic associations between providing food and caring, in conjunction with a widely-held assumption that nutritional support is beneficial, the literature and survey results do not support these beliefs. In fact, studies of nutritional support, in general, show no benefit. It may even be harmful. Available literature suggests that hydration is also not beneficial in terminal patients. Although the author's study relied on nurse perception, early surveys show a high degree of concurrence between families and nursing staff. In addition, more objective measures of patient suffering require further development.

The authors conclude that malnutrition may be part of the adaptive process of the body to counteract tumor growth and to allow the patient to die with less suffering. Artificial nutrition and/or hydration may in fact do more harm than good, and patients have the right to refuse such treatments.

Medications," Journal of the American Medical Association, 244:21 (November 28, 1980).

This article describes the treatment of mild, moderate and severe cancer pain with orally administered medications. For mild pain, aspirin or acetaminophen is the indicated drug. For moderate pain, drug combinations, such as aspirin or acetaminophen and codeine, have clearly demonstrated significantly greater pain relief than single drug constituents alone. For severe cancer pain, physicians generally use narcotics administered parenterally.

Onofrio, B.M. and Yaksh, T.L., "Long-Term Pain Relief Produced by Intrathecal Morphine Infusion in 53 Patients," Journal of Neurosurgery; 72:200-209, February 1990.

This article discusses the analgesic effects of morphine administered to 53 terminally ill cancer patients through chronic, totally implantable infusion pumps. Patients participating in the study had to meet several criteria relating to type of therapy, type of pain, and prognosis for survival. The Infusaid 100 and 400 model pumps and preservative-free morphine sulfate were used. The patients were examined when the pump first required refilling (17-28 days postoperatively) to assess wound healing and extent of pain control.

The type of cancers being treated varied from colon cancer (9 patients) to esophageal or neck (1 patient) and patients experienced a wide range in duration of pain prior to the pump implantation. Thus, intrathecal morphine administered continuously by chronically placed pumps can yield clinically relevant and statistically significant reductions in the patient's pain state. In addition, these data indicated a large margin of safety in terms of tissue toxicity for even supramaximal morphine concentrations.

Patt, R.B. "Nonpharmacologic Measures for Controlling Oncologic Pain." The American Journal of Hospice and Palliative Care, pp. 30-37; November/December 1990.

Nonpharmacologic (as opposed to the traditional concept of pharmacology) approaches tend to be more foreign to the primary provider than traditional pharmacologic interventions and their use typically requires a consultant or outside specialist. The technology associated with providing subcutaneous and intravenous opioid infusion is "simple, portable, relatively inexpensive, and safe. Treatment is readily adaptable to the home-care environment." The analgesic effect of these approaches may be substantial because the drug is delivered efficiently to the site where it is most effective. Improved comfort and reduced side effects are also associated with these interventions. Use of these interventions is indicated when more traditional methods have resulted in either intolerable side effects or inadequate pain relief.

There are a variety of alternatives for continuous drug delivery. Portable and fully implantable infusion pumps are used. The implantable pumps are costly (generally more than $5,000) but are reliable. "Little research into the relative costs of alternative methods of symptom control" has been conducted. Some studies indicate that "despite large initial costs, the totally implantable systems become cost effective within about six-months of implantation because there is no need for tubing changes, a leased pump, additional home care services, etc. In addition, future development of more receptor-specific drugs implies that side effects may be eliminated entirely."

Other approaches include nerve blocks, peripheral nerve blocks, sympathetic nerve blocks, and spinal/intrathecal blocks. These typically follow first line therapy of pharmacologic management. The author concludes that "common sense use of opioid analgesics provides a high quality of pain relief for probably 70 percent to 80 percent of patients with malignant disease."

Patt, RB. "Interventional Analgesia: Epidural and Subarachnoid Therapy," The American Journal of Hospice Care, pp. 11-14; March/April 1989.

Epidural and spinal opioid therapy is considered by this author as interventions at one "extreme of the spectrum of interventional analgesic treatment." These treatment methods are similar, and refer to administering small doses of narcotics directly to central nervous system (CNS) locations in order to relieve pain. Their main advantage is the selectivity of the analgesia and that smaller doses are required to deliver high levels of pain control. In addition, transition from more traditional forms of analgesic administration is associated with reductions in opioid-mediated side effects. Indications for use of these administrative methods relate to associated side effects and whether or not pain control provided by traditional, more conservative methods is adequate.

Epidural catheters can be put in place under local anesthesia in approximately an hour, and a few days hospitalization may be required to arrive at appropriate narcotic dosage, educate the family, arrange home care, etc. Subarachnoid catheter placement is usually implemented by a neurosurgical team and is associated frequently with an implanted infusion device. Although complete internalization is advantageous, it is costly.

Dosages required for pain relief range from 300-500 mg daily for oral morphine, 5-20 mg daily for continuous epidural infusion, and 2-4 ml/day for subarachnoid. Narcotic requirements decrease with closer CNS access. The author states that the "cost of chronic intraspinal opioid therapy is difficult to estimate and has not been studied," but claims that epidural implantation should not exceed $1,000-$2,000. In addition, the costs associated with implanting an internalized pump may range from $6,000 to $10,000.

The risks of these methods are minimal and side effects are uncommon and relatively easily treatable.

Portenoy, R. "Drug Therapy for Cancer Pain." The American Journal of Hospice and Palliative Care, pp. 10-19; November/December 1990.

This article provides an overview of the pharmacologic approach to cancer pain management. Drugs used to treat cancer pain fall into three categories: nonopioid analgesics or nonsteroidal anti-inflammatory drugs (NSAIDs), opioid analgesics, and adjuvant analgesics (diverse types of drugs with other primary indications but are analgesic in certain circumstances).

A widely accepted guideline for selecting drugs to manage pain is the World Health Organization's "analgesic ladder." Aspirin, codeine, and morphine are considered the prototypical drugs for this approach. Clinical trials indicate that about 70 percent of patients find pain relief with the optimal use of these three drugs. Once selected, oral administration is the safest, most economical approach if a patient can swallow and absorb the drug. Beyond this, continuous intravenous and continuous subcutaneous infusion are the most common approaches. Transdermal approaches are now rarely used in cancer patients but will be available soon. Appropriate dosing is necessary to sustain effective pain relief. Controlled release morphine formulations are a significant advance; morphine is gradually released as the tablet moves through the digestive system. As-needed dosing, although it may produce anticipatory anxiety or pain and clock-watching behavior in some patients, still plays an important role in cancer therapy for initial dose titration, rapidly changing nociception, and treatment of breakthrough pain.

When changing drugs or routes of administration, equianalgesic doses should be considered. Most important in opioid therapy, dose should be increased "until adequate analgesia occurs or intolerable and unmanageable side effects develop." In addition, the use of multiple drugs to treat opioid-induced side effects or provide additional analgesia (adjuvant analgesics) is typical in managing cancer pain. The article reviews several classes of drugs and their use as adjuvant analgesics.

Despite the effectiveness of pharmacological approaches, undertreatment is common. Confusion about tolerance, physical dependence, and addiction contribute to undertreatment. For example, physical dependence only implies that abstinence from the drug may be problematic. Psychological dependence, "true addiction," is rare in the cancer population. The risk of psychological dependence, therefore, is low and should not limit the appropriate use of opioids.

Swanson, G. "Patient-Controlled Analgesia for Chronic Cancer Pain in the Ambulatory Setting: A Report of 117 Patients," Journal of Clinical Oncology, 7:12 (December, 1989)

PCA is a drug-delivery system which allows patients to self-administer predetermined doses of opiate analgesics. This is a system for patients in severe pain; it includes the provision of continuous narcotic infusion and the administration of a PCA bolus (a large volume of fluid given intravenously and rapidly at one time for immediate response) for the treatment of intensified pain.

Narcotic analgesics are the cornerstone of moderate to severe cancer pain management. Most cancer patients initially can be managed with oral medications but, as their disease progresses, alternate routes of administration are frequently necessary.

In this study, patients were begun on PCA in both the inpatient, outpatient and home setting with a home-care nurse in attendance. The mean duration of treatment was approximately 3 weeks. When compared to standard postoperative intramuscular injections, patients on PCA experience less sedation and use less narcotics with equivalent analgesia. In addition, these patients express a greater satisfaction with their method of pain control. Relief is more immediate and there is significantly less dependence on nursing or family help in pain control. This study demonstrates that the many cancer patients with severe pain who require parenteral narcotics and are currently treated on an inpatient basis could, with the use of a portable PCA pump, be treated at home. The pumps range in price from $2,500 to $3,500. Medicare currently reimburses for pump rental, morphine administration, and disposables.

Walsh, T.D. "Symptom Control in Patients with Advanced Cancer," The American Journal of Hospice and Palliative Care, pp. 20-28; November/December 1990.

Given a focus of relieving cancer pain, other patient symptoms may be ignored. "A coherent, comprehensive, multi-symptom approach is required to manage patients with advanced cancer effectively." The most typical symptoms affecting advanced cancer patients are pain and anorexia, followed by weight loss and/or anorexia, weakness, constipation (not necessarily in that order). All patients are multi-symptomatic and the distribution of symptoms depends on the primary site and nature and extent of metastases. The author outlines nine principles of comprehensive, aggressive symptom control. Providing comprehensive services to both the patient and the patient's family is essential to caring for all potential symptoms--including financial difficulties, family fatigue, and emotional distress.

Radiation therapy can have an immediate, substantial effect on several symptoms. The role of chemotherapy in providing palliation as opposed to curing the cancer is not well understood. Corticosteroids can be used to treat raised intracranial pressure, spinal cord compression, anorexia, and intestinal obstruction; however, continued treatment with corticosteroids increases the chance of toxicity. In addition, the weight loss frequently associated with terminal illness is not well understood and artificial feeding is very controversial.

While much funded research has focused on evaluating new medications for cancer chemotherapy, little to none has focused on understanding the role of certain drugs in treating the range of symptoms associated with advanced cancer.

Wener, S. "The Pain of Cancer; Control in the Hospice Setting," Postgraduate Medicine, 84(5):79-83,86,89-92; October, 1988.

This article reviews analgesic drug therapy for chronic pain in cancer patients. In the hospice setting, analgesics play a prominent role in alleviating pain and suffering. Opioids and nonopioids are two distinct groups of analgesics.

Nonopioid analgesics (including aspirin and NSAIDs) do not lead to tolerance development or physical dependence. Aspirin is the standard of comparison for this group. Average prices for nonopioids range from $2.55 for 12 300-mg suppositories of acetylsalicylic acid to $12.71 for 50 600-mg tablets of ibuprofen. For treating moderate-intensity pain, nonopiod-opioid combinations are used. Average prices for these products range from $10.20 for 100 Roxicet tablets to $68.41 for 100 Tylenol w/codeine elixir preparation.

For higher intensity pain, opioid treatment is used. Opioids produce no ceiling effect but side effects may prevent high dose usage. While all these drugs have similar efficacy, they vary in potency and/or affinity for binding sites. Morphine is the prototypic opioid agonist. In at least 90 percent of patients, intractable pain can be adequately controlled with morphine, usually given in oral form. Continuous infusions and parenteral use have their proponents, but the oral form is usually given in the hospice setting. Sensitivity to morphine increases with age, thus the effect is more intense and the duration more prolonged in the elderly. According to the author's review of other articles, the amount of morphine given at one time has ranged from 2.5 to 1,200 mg and the usual maintenance dose is less than 20 mg. Doses should be incrementally increased if the pain does not cease.

Costs for morphine depend on the delivery system and/or route of administration: costs (from one company) range from $5.96 for 100 ml oral solution of morphine sulfate to $71.25 for 250 30-mg morphine sulfate tablets. Side effects include constipation, nausea and vomiting, and sedation, but use is usually not limited by these side effects. Use of laxatives is routinely recommended. While tolerance and physical dependence may occur in the hospice setting, they are not clinical problems. Psychological dependence (addiction) is rare in the hospice setting. Drug-seeking behavior caused by unrelieved pain can be attributed to undertreatment and is not a sign of psychological dependence.

APPENDIX C

Summary of Panel Deliberations

NATIONAL CLINICAL PANEL ON HIGH COST HOSPICE CARE

SUMMARY OF PANEL MEETING DELIBERATIONS

December 13-14, 1990

SECTION 1: BACKGROUND AND DEFINITION OF THE PROBLEM

THE CHARGE TO HCFA AND PURPOSE OF PANEL MEETING

According to Section 6016 of P.L. 101-239, the Health Care Financing Administration (HCFA) is charged with conducting "a study of high cost hospice care provided to Medicare beneficiaries under the Medicare program, and evaluate the ability of hospice programs participating in the Medicare program to provide such high cost care to such patients." Based on this study, HCFA is to submit recommendations to Congress to compensate hospice programs for providing such high cost care. The purpose of the panel meeting was to provide one source of input for developing these recommendations. As presented, the charge to the panel was to discuss the clinical use and appropriateness of various types of clinical interventions or procedures that are considered to be high cost.

The panel assembled to discuss these interventions and procedures included leading experts in fields relevant to the provision of palliative care to hospice patients. Specifically, the panel included an oncologist, a pharmacist, an ethicist and hospice medical director, a neurologist, a clinical nurse, an AIDS expert, an anesthesiologist, and representatives from both the National Hospice Organization (NHO) and the Hospice Association of America.

CURRENT HOSPICE REIMBURSEMENT STRUCTURE

Under Medicare, hospices are paid one of four predetermined daily rates for each day a patient is enrolled under the Medicare hospice election. The payment varies according to the level of care provided to a patient on a particular day. These payment rates, prospectively set by HCFA (updates are set by Congress), include:

- **Routine Home Care:** hospices receive $79.74 per diem in FY 1991 for patient days spent receiving care at home, provided by hospice, and not receiving care at any of the other three rates.

- **Continuous Home Care:** for FY 1991, hospices receive up to $465.40 for a day when, in order to maintain the terminally ill patient at home, nursing care is necessary on a continuous basis during periods of crisis. The preponderance of

care must be skilled nursing care, although home health aide and homemaker services or both may also be provided. The continuous home care rate is intended only for periods of crisis where procedures are necessary for control of patient symptoms and require a higher level of care. The actual payment amount depends on the total number of hours this level of care is provided. At least 8 hours are required to qualify for this level of care and the full rate is converted to an hourly rate if less than 24 hours are spent in this care category.

- **Inpatient Respite Care:** a patient may be institutionalized for a short period to provide care, giving relief to family members or others providing care to the patient. The per diem rate for respite care is $82.48 in FY 1991.

- **General Inpatient Care:** this category covers short term inpatient care to perform procedures for acute and chronic symptom control. The per diem rate is $354.73 in FY 1991.

These rates are intended to cover every service provided under the Medicare hospice benefit except hospice physician services, which are paid separately on a reasonable charge basis. In addition, these rates are subject to regional wage index adjustments.

Hospices bill Medicare for the number of days of each type of care rendered to their patients. Medicare reimburses based on appropriate per diem rates. Routine home care accounts for over 90 percent of billed days (and accounts for 86 percent of Medicare reimbursements for hospice care). Due to the nature of the payment system, billing data do not show the specific types of services provided to the patients. In addition, with the exception of the routine home care category, cases are subject to medical review. According to panel members, the extent of review varies across fiscal intermediaries.

Medicare payment is also subject to an overall cap of $9,787 per patient (for the cap year ending 10/31/90). The cap is applied on an aggregate basis (e.g., for 10 patients, the total reimbursement for their care is compared to 10 x $9,787). Thus, while one patient could require care costing greater than $9,787, other patients at the hospice for whom costs are not as high could offset this case and the aggregate cap would not be reached. Currently, no hospices have approached this cap.

In addition, Congress placed a limit on use of inpatient care. No more than 20 percent of total days spent under the Medicare hospice benefit can be for inpatient care. There is a reimbursement formula used to pay hospices, which effectively reduces reimbursement to the routine home care level for inpatient days in excess of the limit. This limit resulted primarily from legislative intent to emphasize home care rather than institutionalized forms of care.

There are only two circumstances under which a Medicare hospice patient can receive Medicare payment for services provided outside the scope of Medicare hospice benefits: 1) when the patient requires treatment for a condition unrelated to the terminal illness; and 2) when services are provided by the patient's attending physician. Care which is unrelated to the terminal illness and attending physician services are not considered hospice care and are not counted in applying the aggregate cap. Physician consultation services can be billed for separately from the aforementioned per diem rates.

DEFINING THE HIGH COST PROBLEM

An explicit definition of the high cost problem was not developed. However, through the course of the deliberations, panelist discussion implied that, while the basic payment rate is adequate, there exists a set of high cost interventions or procedures provided to a few patients which in the short run may result in financial risk to a hospice provider. These patients could be considered outlier cases and, particularly for smaller hospices, represent a large expense for the hospice provider.

The panel's role was to identify what these high cost procedures are, their use and costs, and to contribute to HCFA's recommendations for modifying the current reimbursement structure and ensuring the appropriate provision of these interventions. However, there is a dearth of data available to identify the use and costs of these interventions and to claim with certainty that a high cost problem defined in this way exists. Much of the evidence is anecdotal. In addition, as one panelist pointed out, it is hard to prove that hospices need these more expensive forms of care to provide hospice services.

The panelists agreed that many hospices are struggling with the costs of providing newer, sometimes more technologically sophisticated and sometimes more expensive medications and/or modes of administration, and, thus, some type of high cost problem does exist. The panelists initially defined the nature of the cost "outlier" problem as an access issue: 1) access to hospice care by populations currently underserved or not served by hospice programs; and 2) access to more expensive care by patients in the hospice system who are at high risk for needing these forms of care.

Access to Care For Populations Currently Not Served or Underserved

There was extensive discussion about access to care for populations for whom hospice care might be beneficial but not routinely provided. These populations include the indigent or homeless who are unlikely to receive hospice care because they lack a primary caregiver or live in a situation that is unsuitable for the provision of home care. Although hospices are not required to provide personal or custodial care, some may try to provide it and thus face additional costs. Some of these patient populations may have access to care through other programs. For example, AIDS patients may have

access to care through programs supported by the Federal Government's AIDS initiatives. In addition, panelists identified another patient group that is underserved: the potential hospice patients that are diverted directly or redirected away from the hospice system because they are likely to need either extensive inpatient care or expensive forms of treatment. Medicare patients in this group would continue to receive hospital, skilled nursing, and home health care under Medicare Part A and Part B programs.

Panel members, in general, agreed that access issues for individuals who are homeless or have home situations unsuitable for the provision of home care are important in terms of broader concerns about the provision of and reimbursement for hospice care. Several panel members agreed, however, that the focus of these deliberations should be on the high cost interventions and procedures provided to patients currently in the hospice system and may present financial risk to a hospice provider. Although one panel member felt that access to high cost forms of care was linked to high costs associated with lack of a home or caregiver, panelists generally viewed larger concerns about increasing access to care as a separate issue from high cost medical procedures or nursing care.

While panelists felt that it may be more difficult to distinguish the potential patients who are denied care because they are at risk for needing high cost treatments, the immediate need is to concentrate on the small number of "outlier" patients, not the populations of terminal patients who are underserved or nonserved by hospice programs.

Specifically, the panel members endeavored to focus on the need to identify those interventions "needing more than a nurse by the bedside, what the associated parameters are, and modify the system so that barriers to providing these services no longer exist."

Individuals At Risk for Requiring High Cost Interventions

Panel members estimated that the number of individuals requiring high cost interventions is unlikely to be more than 10 percent of all hospice patients. They discussed provision of care to these individuals from two perspectives: 1) how a reimbursement system should be structured to finance hospice care for these individuals; and 2) how the current reimbursement structure is affecting the provision of hospice care for these individuals. Under the first category, panelists felt the reimbursement structure needs to be modified in order to provide payment for these higher cost, but perhaps more appropriate, forms of care. Modifications should:

- allow hospices room to say that certain interventions are clinically appropriate without worrying that the expense of providing these interventions could put the hospice out of business;

- allow the provision of services to the small number of patients requiring high cost interventions;

- allow the hospice system to grow as the rest of the health care system does, not only by adjustment according to the hospital market basket every year, particularly if hospice care is substituting for more expensive forms of care, but also by allowing reimbursement for newer, high cost technologies;

- allow hospices to stay current in terms of providing state-of-the-art palliative care without promoting overutilization; and/or

- provide the extra dollars when needed for the few unusual cases.

Under the second category, panelists presented anecdotal evidence of the ways in which the current reimbursement structure is affecting the provision of hospice care. The following points were made:

- Hospices, particularly small hospices that are unable to spread financial risk across a large number of patients, either are not accepting patients who might require high cost treatment or are denying patients in the hospice system advances in therapy because of the associated high costs. Thus, hospices may strictly define their admission criteria--or may not expand their admission criteria as changes in the marketplace occur--so as to allow them to legitimately refuse patients who might need potentially expensive care.

- Potential hospice patients frequently are not even referred to a hospice program because their physicians, discharge planners, or social workers know that they will not be accepted as hospice patients.

- Patients requiring high cost care may revoke the hospice benefit and be admitted to the hospital to receive necessary treatment and thus be involved in "flipping" from one type of reimbursement category into another (e.g., from hospice into home health or hospital inpatient), thereby losing some continuity of care.

- Denial of certain treatments might also occur because hospice staff are not trained in use of a newer procedure and to provide it would require substantial investments in education. Because these interventions appear to happen infrequently, it may not be cost effective for the hospice to undertake these

educational efforts. However, this may not be an issue that changes in reimbursement would address.

Some of these points were elaborated upon more than others. There was extensive discussion about the extent to which large hospices need protection from high cost cases. Large hospices may be able to "self-insure," in the sense that their costs can be spread across a large number of patients. Thus, a few high cost patients may not represent a financial catastrophe for the hospice. Early experience in the Medicare program shows that only large hospices were Medicare-certified. Cost is now becoming a larger issue as smaller hospices are becoming certified, perhaps in response to recent rate increases in Medicare hospice reimbursement (or perhaps a decline of alternative funding sources). However, in conjunction with the development of high cost techniques for pain management, these smaller hospices may be less able to withstand the financial pressure of one or few patients that need high cost treatment. Several panel members argued that it is a myth that only the small hospices needed protection against the high cost patient--large facilities also face extremely high costs. The panelists seemed to agree, however, that the smaller facilities face a greater liability.

There was some discussion of hospices that may have philosophical biases against providing some of the more sophisticated (and thus, perhaps higher cost) interventions. One panel member indicated that in some hospices few of these high cost procedures are performed because these procedures are perceived (by these hospices) as somewhat contradictory to traditional hospice care, thus the financial risk may not be as significant for these hospices.[1] Along these lines, the point was made that the attempt to distinguish between what is curative, palliative, or rehabilitative is not always possible. However, hospices may be refusing to provide these treatments with the argument that they are curative and, thus, not provided by the hospice.

Finally, there was some concern expressed about potential discontinuity in the provision of care, particularly for patients who may be forced to revoke the hospice benefit in order to receive appropriate treatment provided under Medicare acute care benefits. This led to panel consensus that all of the terminal condition health care provided to a hospice patient should be under the control of the patient and hospice provider. Providing more flexible reimbursement might enable hospices to maintain more control over patient treatments for patients who have chosen the hospice alternative.

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[1] The perception that providing some of the more sophisticated and perhaps high cost procedures is contrary to traditional hospice care is not necessarily universally held in the hospice industry.

DATA PRESENTED

Panel members agreed that a major difficulty in sharply defining the nature of the high cost problem is the lack of data to delineate exactly what are the high cost procedures and who are the high cost patients. Thus, although some panel members stipulated that many of the manifestations of the perceived inadequacy of reimbursement listed above are occurring and that they believe some type of problem exists, much of the evidence is anecdotal.

While data that could help to better define the extent and nature of the high cost problem do not exist, there is some information collected on hospice care and on interventions considered by hospices to be high cost. Two sets of data were discussed. The first was some background data provided by HCFA on the number of Medicare beneficiaries and dollar amounts associated with the Medicare hospice benefit. These data provided some evidence of the rapid growth in the Medicare hospice benefit between 1988 and 1989:

- The number of Medicare beneficiaries using the hospice benefit increased 41 percent, from 44,000 in 1988 to 62,000 in 1989.

- The payments for the hospice portion of total hospice-related payments (not including payments for additional care for patients on the hospice benefit) increased 68 percent--from $129 million in 1988 to $216 million in 1989.

- Both length of stay and average reimbursement per patient also increased. Average length of stay increased by 25 percent between 1988 and 1989 (from 37.2 days to 46.4 days). Average reimbursement per patient increased from $2,919 in 1988 to $3,472 in 1989, a 19 percent change.

These data represent aggregate per diem amounts but no breakdown of the actual services provided. In addition, data from a 5 percent sample of Medicare beneficiaries who were hospice patients for some period of time between 1987 and 1989 show an estimated $51 million was spent for Part B outpatient services. However, Part B coverage is only for unrelated services or attending physician services. In addition, patients may not be on the hospice benefit at the time these services were billed. This amount includes payments for ambulance and physician services provided in hospital, office, home, and emergency room settings. Much of the physician billing relates to radiation therapy, planning, treatment, and management, radiologic procedures, wheel chairs, and oxygen equipment.

The second set of data comes from the NHO survey of Medicare-certified hospices. This survey was described as a two-stage survey, and preliminary analyses presented to the panel were from the second stage of the survey. The second stage questionnaire

was sent only to those hospices indicating that they provided at least one of nine procedures considered to be high cost. These nine interventions were listed on the first stage questionnaire: antibiotics, AZT, dialysis, erythropoietin, morphine pump, palliative chemotherapy, palliative radiation, surgery, and total parenteral nutrition (TPN). For each of the interventions that the hospice indicated they provided, the hospice was asked to provide information on the additional costs of providing that particular service to their patients requiring this care. Panel members raised several concerns about the data collection and presented results (which will be discussed in a more detailed analysis of the data in the final report).

In general, the data were viewed as of limited usefulness in the preliminary form presented, since they were not collected in a rigorous manner. The point was made that cost and use data for these procedures are very difficult to gather and that, currently, little data exist that provide this information specific to hospices. Most panelists agreed that these data represent a first cut at the problem but must be interpreted with extreme caution. The panel also felt that there is a need to do well-controlled research in this area.

SECTION II: PROCEDURES AND SUGGESTED MODIFICATIONS

GENERAL CONSIDERATIONS

The panelists felt that several points raised early in the discussion, and reiterated throughout both days' deliberations, should be highlighted as a set of general considerations. These considerations provide a context within which their list of high cost interventions and suggested recommendations should be reviewed. These considerations are listed below.

- The intent of the panel was to discuss potential modifications to the reimbursement system that would accommodate circumstances under which palliation of symptoms is provided by a high cost intervention (after less costly alternatives have been found to be inadequate).

- The patient and hospice provider should have control over making decisions about whether or not particular interventions are medically appropriate (e.g., non-hospice personnel should not be guiding the choice of treatment or the reimbursement structure should not be forcing choice of treatment).

- There must be medical guidelines or standards in place in order to provide some check against misuse or abuse of the identified interventions once reimbursement is available. These guidelines should be established by a group of people experienced in providing hospice care (e.g., hospice medical directors) and in

pain management techniques. While this may seem contradictory to the above bullet point, panelists felt that nothing can or should be done without clearly indicating the well-being of the patient and involving the patient's caregiver. More costly interventions should be used only when less costly appropriate alternatives have been evaluated.

- As an additional check for misuse and/or abuse, some type of utilization review mechanism ought to be put in place.

- If modifications to the reimbursement structure are made, evaluation of the impact of these modifications (particularly in terms of patient access to hospice care and the effect of availability of additional payments on treatment patterns) should be undertaken.

- Although a list of interventions was developed by the panel, it was felt that more research on which types of interventions, or groups of interventions, are costly and how frequently they are used should be performed.

IDENTIFYING HIGH COST PROCEDURES

The panelists felt that the lack of data on use and costs of various procedures, and on an appropriate benchmark for comparison, hindered their ability to define a list of specific procedures or interventions and why these interventions represented a high cost problem. However, the panelists discussed a variety of ideas, developed a list of categories for probable high cost interventions, and suggested mechanisms for providing reimbursement for high cost interventions.

High Cost Indicators

The panelists agreed that it was possible to identify some types of treatment interventions which typically result in high costs. In addition, the panelists discussed whether there are indicators that would identify patients likely to need expensive treatments or likely to become more costly. Indicators imply that a high cost patient can be readily identified at the point of admission to the hospice. One panelist discussed some research efforts aimed at categorizing hospice patients into discrete groups based on distinct characteristics (similar to the Resource Utilization Groups for nursing home patients) but indicated that nothing concrete had yet materialized.

Some examples of potential indicators were discussed. These included a diagnosis of AIDS and patients presented with difficult to manage pain. However, after some discussion, the panelists agreed that indicators of high costs should not be disease-specific as this may discriminate against patients who do not have that particular disease but may present with the same type of potentially high cost needs. In addition, high

costs associated with AIDS patients were noted to be typically associated with intravenous (IV) antibiotic administration. This indicated that there might be a broader categorization (e.g., of high cost interventions) which would incorporate high costs associated with particular diseases. Difficult to manage pain was also discredited as an indicator because it could occur at any point during a patient's stay in hospice. Thus, a patient that initially may not appear to need high cost types of care may develop these needs at a later point during their stay.

Another potential indicator discussed was where and how patients were entering the hospice system: from an acute inpatient setting or an outpatient setting. Patients entering from an acute inpatient setting may already be on IV medications and may continue to need high cost types of pain relief. Some panelists indicated that it is often difficult to discontinue interventions once a patient was admitted, even if the intervention is considered inappropriate by the particular hospice. Source of referral also was disputed as an indicator, however, because patient referral patterns are difficult to generalize and may be dependent on the particular hospice program's associations with home care agencies and hospitals in its service area.

While there was some discussion that patients likely to require surgical interventions were easy to identify, other panelists maintained that this was not the case. For example, surgical interventions may become necessary for those patients with whom the hospice has tried everything else but the patients still have difficult to manage pain, a situation that cannot always be predicted. Surgical interventions also may be needed for the patient who has been mismanaged. A patient may also end up in the hospital for a redetermination of what the problem is, what made the situation go awry, and what can be done to improve the patient's condition in the shortest amount of time. Thus, in general, panelists felt that it would be difficult to determine a priori whether a patient would be a high cost case.

List of High Cost Interventions

Discussion of a broad list of procedures and interventions considered to be high cost was initiated by one panel member's suggested list. Most panel members felt comfortable with this list as a reasonable starting point, with some refinement. This suggested list identified the following as high cost interventions:

- IV administration of pain medications, antibiotics, or other symptom relief; transfusions; hydrations; and TPN therapies;
- subcutaneous administration of pain medications;
- palliative chemotherapy (oral or continuous IV);

- palliative radiation therapy;
- aerosolized pentamidine; and
- AZT.

Several allegations were made about why the current reimbursement amounts were not covering the costs associated with these procedures and the problems associated with providing additional reimbursement. First, when the hospice legislation was initially discussed and enacted, the types of technologies listed were not generally available in the home care setting. Historically, there have been many hospices that rely on "low tech" management and intervention. While some newer types of interventions (medications, equipment, and technologies) may be more expensive, the panelists agreed that reimbursement should be available as these interventions might be more efficient, appropriate, and generally better than traditional methods. Building on this point, some panel members desired to develop a list of types of interventions that would allow for future technological developments to be incorporated in the reimbursement structure without having to continuously rework the list.

Second, several panel members discussed concerns about hospice reliance on whether reimbursement exists or not as a primary determinant for use of a particular intervention. Panelists felt that existence of reimbursement might become the rationale presented to the patient for using a particular intervention, instead of discussing with patients the clinical rationale for using or not using the particular intervention. There was also concern about inappropriate increases in use of an intervention once additional reimbursement was provided. It was in this context that the need for guidelines (mentioned as a general consideration) became most apparent and important.

Panelists felt that any reimbursement for use of an intervention should be based on appropriate use as stipulated in a set of guidelines or standards. Because hospices may find it difficult to stop an intervention once it has been initiated, these guidelines may need to be different for instituting the intervention after the patient enters hospice versus continuing the intervention if the patient enters hospice already receiving the intervention. In addition, guidelines would need to be specific enough to identify, for example, when hospice staff should start patient controlled analgesia (PCA) infusions versus when they should be provided by an outside contractor. It was noted that the Agency for Health Care Policy and Research (AHCPR) is currently developing pain management guidelines, but panel members felt that these guidelines may be too broad and not specific to hospice.

Guidelines should be specific to hospice because terminal illness is treated very differently in hospice settings than in acute care settings. However, some situations were identified as consistent with hospice care that would not easily fit into the types of

guidelines being discussed. One example was of a young mother who is terminally ill but wants to live until Christmas. This may require the use of TPN, which is not generally used in terminal care. In addition, while panelists felt guidelines for use were important, they acknowledged the difficulties in establishing such guidelines. A major difficulty is that the effectiveness of each modality on hospice patients has not been definitively established by hospice-relevant research and existing evidence has not been widely published, thus hindering development of reasonable practice guidelines.

Third, there was some discussion about the role of patient choice in using any of these procedures and ethical concerns associated with the restriction or implementation of high cost treatments. For example, it was noted that if there is a particular intervention that a patient requests or insists upon having, there is added pressure to provide that intervention, even if it is not a medically necessary procedure. Some panel members, however, argued that most patients will either shy away from high tech interventions, or will retreat from demanding them, once the full range of options and their associated risks and benefits (not necessarily costs) are explained.

Refining the List of Interventions

Specific refinements to this list were proposed. One panelist suggested changing the entry of subcutaneous pain medications to nonenteral analgesics so that the category would include all parenteral and intraspinal analgesics as well as other future developments such as transdermal patches. There was some argument that transdermal patches were already in use and conceptually accounted for in the intent of the original legislation as "low tech," noninvasive treatments. Some panel members noted, however, that while some patches currently in use may indeed be inexpensive (e.g., scopolamine patches at $3 each), newer, soon to be available, patches--which may have some real advantages for hospice patients--will cost over $150 each (e.g., fentanyl patches).

This discussion raised a complicating issue: that procedures not requiring additional supplies or equipment, even if the medicines themselves are expensive, should be left off the list of high cost procedures. While it was noted that often the mode of administration is what leads to the higher cost of an intervention, not the drug specifically, some panel members cautioned against assuming only high tech interventions are high cost. Some "low-tech" and/or noninvasive treatments may also be high cost. Panel members seemed to agree that cost was the appropriate focus.

A question was raised concerning the inclusion of AZT on the list of high cost procedures. There was some discussion that AZT is fairly widely used in major centers where large clinical trials may have taken place but perhaps this is not true in other settings. However, if the goal of the recommendations is to be futuristic, it would be useful to assume wider availability of AZT in the future. Other AIDS medications were

also mentioned, such as ddI, that may mean the introduction of a whole new family of drugs that may be high cost, or need high cost modes of administration.

Rather than identifying specific medications, such as AZT and aerosolized pentamidine, the suggestion was made to have a broader classification, such as high cost medications. This would involve, however, determining a cost threshold above which some level of reimbursement would be provided. One suggestion was to consider every drug which costs higher than some percentile of the average wholesale price of drugs, as long as the drug was used appropriately. The panel agreed that some threshold cost should be determined; although, without useful cost data this would be difficult. This type of mechanism, however, was deemed preferable to identifying specific medications or products.

During further discussion, the panel agreed that the cost of the drugs should be standardized to some indicator, not just based on a per tablet cost. For example, cost per treatment regimen or per month of use could be used to standardize the costs. In addition, it was suggested that the costs should be compared to drugs normally used in palliation of symptoms of terminal disease rather than all drugs, because some drugs that are very expensive to use in a hospice setting may not be at all expensive in an acute care setting. One panelist pointed out that cost estimates should also include labor costs. For example, IV morphine is a low cost drug, but the associated labor required (pharmacy, preparation of cassettes for PCA or infusions, extra nursing visits) can be very expensive.

Rather than defining an intervention per se, the panel discussed alternative approaches such as reimbursement for expensive modes of administration (supplies and durable medical equipment) and for expensive drugs (those over some threshold cost adjusted to some standard for measurement), and, thus most of the categories originally listed still would be covered. The original list of high cost interventions became modified as follows:

- IV administration of pain medications, antibiotics, transfusion, hydration, TPN, and chemotherapy;
- medication delivery systems that require intraspinal and continuous subcutaneous access;
- drugs costing greater than X percent of drug costs normally used for palliation of terminal illness; and
- palliative radiation therapy.

Attached to this list would be a statement defining total costs as the costs for supplies, equipment, drugs, and labor. There was some concern about including labor because the incentive to contract out for everything would be introduced. The issue of labor costs was also raised because the costs of some therapies provided through outside contracts are for a treatment package inclusive of labor. It was suggested to include under costs, then, the costs of supplies, equipment, and drugs. Labor, if provided through a vendor contract, could be included if necessary.

Exclusions Process for Surgery and Radiation Therapy

One panelist's suggested recommendation was that surgical procedures, both those related and unrelated to the terminal illness, should be considered as exclusions from the Medicare hospice benefit and be covered under Medicare Part A. This option also was suggested by other panelists early in the deliberations. Surgical procedures were considered easy to identify as producing cost outliers. Palliative radiation therapy, however, was not as readily agreed upon and warranted further discussion.

Surgical interventions were viewed as less discretionary than other types of procedures and as a distinct end of the treatment continuum. In addition, panelists noted that surgical interventions are likely to be appropriate for only a small number of patients. However, surgical interventions are also likely to be extremely expensive and relief from the costs of providing surgery was seen as an immediate need. Several questions were raised about defining which surgeries are considered high cost:

- Should excluded surgeries be only those related to the patient's terminal illness?
- Would all the various types of neuroablative procedures fit into the category of surgery?
- Should the placement of an IV catheter via a central line be considered surgery?
- Should surgery be limited to procedures done in an acute care setting?
- Should surgery be limited to only those procedures performed by a surgeon?

Although the panel agreed that surgery was the only high cost intervention for which a reimbursement decision could be made quickly, they felt that more work needed to be done in specifically defining which surgical procedures are high cost.

Another suggestion was that, similar to arrangements with outside contractors for some services (such as some types of IV therapy), contractual arrangements to provide certain types of surgical procedures could be made with hospitals. However, it was

pointed out that hospices need some market power and negotiating savvy to realize this type of arrangement.

There were two concerns about this type of arrangement. First, it puts pressure on the hospital because the patient shows up on the computer screen as a hospice patient and the hospital bill is initially denied. The hospital must then go through an appeals process. It might be quicker to go through the hospice, as typically is done with consultant billing. Second, some panelists felt that hospices would want to be careful about unbundling procedures related to the terminal illness in this way. Instead of gaining more control over the care of the hospice patient, this method may introduce additional players and further disrupt continuity of care.

For palliative radiation therapy, one panelist presented the idea that radiation therapy is not distinct from surgery in the sense that it is a local treatment for a local problem and should therefore also be a candidate for exclusion. Thus, although palliative radiation therapy was listed as a high cost intervention, there was some discussion about whether it should be treated in a similar fashion as surgery. Some panel members pointed out that surgery is a known extreme cost to the hospice program and is easier to single out as a one-time event, whereas radiation therapy is less easy to distinguish from the continuum of care and may not be all that expensive. There was also some concern that radiation therapy, because it involves less invasive techniques, will be provided in a less discretionary manner than surgery. Thus, given additional reimbursement for both surgery and radiation therapy, there is more likely to be inappropriate increases in use of radiation therapy than in surgery. Although the discussion was inconclusive, palliative radiation therapy was left as a high cost intervention.

Final List of Panel-Recommended Interventions

There was some concern about how the list of interventions and exclusions for surgeries related to one another. One suggestion was to exclude surgeries except those related to the set of interventions identified on the list (e.g., placement of a central line). These surgeries (such as decompression of a spinal cord net metastasis, hip fractures, and bowel obstruction surgery) are those known to be high cost outliers for hospice programs. For these surgeries, the patient would be admitted to an acute care setting, the hospital would bill under an existing surgical code, and reimbursement would be provided under Medicare Part A. All surgical procedures related to the terminal illness would thus be added to the list of high cost interventions because procedures unrelated to the terminal illness are already covered through Medicare Part A. This would also eliminate the problem of identifying precisely which surgical procedures would be eligible for exclusion.

After several rounds of discussion about surgical exclusions and the list of high cost interventions, the panelists felt comfortable with including surgical procedures related to the terminal illness as a high cost intervention. The revised version of the list would appear as follows:

- IV administrations for pain medications, antibiotics, transfusions, hydration, chemotherapy, and TPN
- Medication delivery systems that require intraspinal and continuous subcutaneous access
- Palliative radiation therapy
- Surgeries related to the terminal illness
- Drugs that cost more than X percent of average cost of drugs normally used in palliation of symptoms for terminally ill patients.

As with an earlier version of the list, there would be an additional statement that total costs refer to cost of supplies, equipment, and drugs, and may include labor. Panelists also agreed that further work needed to be done to identify the appropriate cost threshold. Despite identification of high cost procedures, the panelists felt that more work needed to be done before a reimbursement policy for medications could be appropriately structured. There is a more immediate need to cover the costs of extreme expenses (e.g., expenses for surgical interventions).

APPROACHES TO FINANCING

Throughout the two days of discussion, several mechanisms through which reimbursement would be provided for high cost cases were suggested.

Exceptions/Exclusion Process

Early in the discussion, this type of mechanism was proposed to reimburse for certain specified interventions that are necessary (e.g., surgical interventions). There was some concern that a patient in a lot of pain or needing immediate attention would have to wait out some kind of prior approval process. It was noted that prior approval would not have to be incorporated; however, what is more likely is that the procedure would be performed and then the hospice would have to justify the procedure during a review process and support it with documentation.

As previously mentioned, a particular concern about the exceptions process was that providing additional reimbursement for specific procedures or interventions outside the

per diem rate for hospice care could encourage overutilization of that procedure or intervention. While panelists felt that financial provision for any intervention will encourage its use, they believed that guidelines for use would reduce overuse or abuse. Inappropriate use could be particularly problematic with interventions for which appropriateness is not clear-cut, given alternative therapies. A suggestion to mitigate overuse was to provide an allotment of exceptions, which would force providers to think carefully about which excepted procedures to provide or for which case the procedure is most applicable. However, it was felt that an allotment approach would not solve the problem, as the next patient requiring the procedure would still be shunted to the acute care system if the allotment of exceptions is exhausted.

A similar notion was also presented for high cost medications. As with certain drugs used in dialysis, specified drugs might be paid for outside the regular rate on the theory that they are not given to all patients, are not routinely used, and thus should be considered as separate from a composite rate. The problem of identifying specific drugs still remains, however.

Risk Pool

One suggestion was to create a pool of funds available to hospices for reimbursing high cost cases. This mechanism was proposed as a way to eliminate some of the barrier to providing care because a patient's potential expenses were prohibitive. Thus, a hospice could be reimbursed for catastrophic costs. However, there was considerable concern that establishing a pool of funds by setting aside some amount out of the total available funds for hospices would reduce the hospice reimbursement rates, rates which hospices contend already do not cover costs.

This suggestion arose from a discussion of total funding for hospice care. There was some attention given to the proportion of total Medicare dollars currently paying for hospice care, and how the proportion of the total could be increased by including as hospice reimbursement payments for procedures currently used by hospice patients but under some other reimbursement category (e.g., home care, skilled nursing facility or inpatient care). The panel felt that many procedures are being done but not reimbursed through the hospice benefit. Thus, it could be a "cost-neutral" approach to shift reimbursement from these other areas to hospice, if services from other providers were then denied, and thus allow hospices to maintain some control over the care of the patient. Currently, according to 1989 HCFA data, hospices are receiving, on average, approximately $3,500 per patient with an average length of stay of 46.4 days.

Cap on Number of Outliers

Another suggestion was to impose a cap on the number of patients who could be classified as outliers in any year; for example, 10 percent of patients in a given year.

For those outlier patients, some additional payment amount per day could be provided (e.g., $15). Similar to providing an increase in rates, the outlier problem for extremely costly cases would remain unresolved, however. In addition, it was expressed that reimbursement should be appropriate for the patient mix of a particular hospice, not arbitrarily set at 10 percent of patients.

Decreasing Partial Reimbursement

In response to concerns about specifying a list of procedures or interventions, one panelist suggested a system in which hospices would receive, for the small number of outlier high cost patients (example given was 10 percent of patients), a decreasing percentage of the increased cost. For example, above the approximate $3,500 per patient (spent by Medicare)[2] up to $10,000, hospices would receive 80 percent; for costs between $10,000 and $15,000, hospices would receive 50 percent, etc. This type of system would eliminate the need to identify specific procedures or particular qualifications and lessen the risk of not being able to predict future high cost cases. In addition, given concerns about inappropriate increases in use, partial reimbursement would provide incentives for using the procedures but will require some discretion in choosing to use them. This suggestion, however, was problematic because it would move reimbursement toward a mixed, cost-based system, which is precisely what HCFA would like to move away from.

Establishing A Fifth Reimbursement Category

Another suggestion was to establish a fifth category of care in addition to the four current hospice reimbursement rate categories. Cases in this category would be subject to review, but the decision-making process regarding what interventions to use would still be in the control of the hospice provider. Other panel members, however, felt that the high cost problem is an intermittent problem and not consistent enough to warrant establishing a fifth category of care. In addition, it was noted that it would be difficult for the fiscal intermediary to determine when a patient was in the fifth level of care unless carefully defined criteria were established.

General Rate Increase

More than one panelist raised the suggestion that perhaps the daily rate itself should be revisited and that a small increase in the daily rate might solve the marginal problem of high cost patients. However, it was pointed out that raising the average rate a little bit would not solve the outlier problem if surgery, for example, is indeed prohibitively

[2] This figure was approximated from 1989 HCFA data presented earlier: $216 million/62,000 beneficiaries = approximately $3,500 spent per beneficiary

expensive. This might be particularly true for small hospices where the numbers of patients are so small that an increase in the daily rate still will not cover the costs of providing care to the outlier case. The problem remains because there are not enough patients over whom to spread the costs.

OTHER ISSUES

Recommendations for Changing Billing Procedures

One suggested modification to current procedures was to modify the way hospices bill for services. One panelist suggested that hospices need to recognize that there is a theoretical limit to the aggregate amount that Medicare can spend of $9,787 per patient (although not an appropriated amount). Part of the problem is that modifications need to remain budget neutral or additional monies will have to be found somewhere. By recognizing this theoretical limit, and billing appropriately, more of the funds currently spent on providing these services, but accounted for under other reimbursement categories, could be shifted to hospice (again assuming that the care being provided under other reimbursement categories is denied).

Other Types of Outlier Expenses

An additional recommendation was to consider as outlier expenses bereavement costs, care provided to hospice-appropriate patients, and the potential added expense of persons without a primary care provider. For example, bereavement counseling is the only mandated service which is to be provided after the death of a beneficiary. Reimbursement for these services is not available, however, and little is known about what they cost.

Research Agenda

Several panelists felt it was important to specify areas where further research is needed. For example, panelists agreed that quantitative information to address many of their questions does not exist. Their questions included:

- What does it really cost to provide particular types of treatment (average cost to the hospice of providing care)?
- What is the frequency of use of high cost procedures in the hospice setting?
- What are the costs of treatment compared to the costs of treatment for individuals left out of the system?

- What is the proportion of patients who go off the hospice benefit to receive a high cost treatment?

- How many patients are denied hospice care because they are likely to require extensive inpatient care?

- How many patients in the hospice system are denied advances in therapy?

- How many Medicare dollars go to providing hospice services versus other services?

Another aspect of identifying research areas is consideration of whether hospices could provide the types of data necessary to answer these questions. When asked what type of research approach would be used, panel members made several suggestions:

- Researchers need to be precise about how they are defining costs. The sample should be large enough to attach some margin of error to the results, and also must be regionally representative, as costs vary. Prospective sampling of two or three hospices will not be enough.

- We need better estimates of the frequencies of use for these procedures in order to understand how many hospice patients receive these procedures and how many really need to receive them.

- A comprehensive study of drug costs to hospice programs would define specific medications that are high cost. One approach would be to identify the costs associated with delivering 100 mg of a medication under every type of administrative mode, in order to identify which modes of administration are most expensive.

- There needs to be a national, multi-site hospice study demonstration to determine the costs and outcomes of hospice care versus conventional systems for terminal illness.

- There should be a study to identify if incorporating homeless people or people without primary care providers in the hospice system would reduce the costs of their care by replacing their use of acute hospitalization, and to what degree doing so would benefit them.

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APPENDIX D

High Cost Intervention Study (HCIS) Survey Form

NATIONAL HOSPICE ORGANIZATION
"HIGH COST" INTERVENTIONS STUDY

PATIENT DATA FORM
HOSPICE ZIPCODE _____

Please provide information about each hospice patient who has received "HIGH COST" HOSPICE INTERVENTIONS, using your hospice's definitions of the term "High Cost Service". Note that the patient may have received one or more of these services during their length of stay in hospice.

_____# Patient Number (Only for identifying study participants)

_____ (ICD9 Code) Primary Diagnosis:_____
_____ (ICD9 Code) Secondary Diagnosis:_____

Please explain other problems/conditions related to the diagnosis. (e.g., presence of bone pain, bowel obstruction) _____

Name each "High Cost" Intervention received per patient during their stay in hospice and describe the "unit of measure" (i.e., visit, unit dose, procedure, day of care) for this service. (A patient may have received more than one type of service) For example:
Intervention #1: Palliative Chemotherapy (visits)

	Name	Unit of Measure
Intervention #1:		
Intervention #2:		
Intervention #3:		
Intervention #4:		
Intervention #5:		
Intervention #6:		

Please explain in detail the rationale for providing these interventions to the patient:_____

Total Number of Interventions Received During Stay in Hospice by Total Costs (may included one or more types of service)

Name of Intervention	Number* of Interventions	Total Costs** of Intervention
#1:		$
#2:		$
#3:		$
#4:		$
#5:		$
#6:		$

* Number defined as the frequency of occurence of the "units of measure" during the patient's stay in the hospice program

Profile of Patient Receiving High Cost Hospice Interventions

___ Sex (Female or Male)

___ Age

Select age from the following:

a. Under 10 years old
b. 11-20 years old
c. 20-34 years old
d. 35-49 years old
e. 50-64 years old
f. 65+ years old

___ Ethic Profile

Select ethnic group from the following:

a. White
b. Black
c. Hispanic
d. Native American or Alaska Native
e. Asian
f. Other

Functional Status History during the following intervals:

___ At Admission

___ During interval when interventions were provided

___ At Discharge/Death

Select Functional Status from the following:

a. Ambulatory
b. Intermittent Ambulatory
c. Non-ambulatory

Pain Level History during the following intervals:

___ At Admission

___ During interval when interventions were provided

___ At Discharge/Death

Select Pain Level from the following:

a. No Pain
b. Mild Pain
c. Moderate Pain
d. Strong Direct Pain
e. Severe Direct Pain
f. Intractable Pain

Health Benefits Status during the following intervals:

___ At Admission

___ During interval when interventions were provided

___ At Discharge/Death

Select Benefits Status from the following: (only one)

a. Medicare Hospice pt.
b. Medicaid Hospice pt.
c. Medicare Home Health pt.
d. Medicaid Home Health pt.
e. Health Insurance Coverage pt.
f. Self-pay pt.
g. Indigent pt.

Length of Stay in Hospice Program (in days)

_____ Length of Stay in Home Care
_____ Length of Stay in Continuous Care
_____ Length of Stay in Inpatient Care
_____ Length of Stay in Respite Care

APPENDIX E

Data Fields and Coding Guide

APPENDIX E Data Fields and Coding Guide

FIELDS	DESCRIPTORS
I PRIMARY DIAGNOSIS, ICD-9	
II TYPE OF INTERVENTION	
	1. Medication narcotic
	2. Medication chemotherapeutic
	3. Medication general
	4. Radiation therapy
	5. Laser therapy
	6. Hyperalimentation
	7. Blood therapy
	8. Supplies
	9. Equipment
	10. Procedure
	11. Hospitalization
	12. Nursing
	13. Enteral nutrition
	14. Hydration (IV) therapy
	15. Physical therapy, respiratory, social work, occupational therapy
	16 Physician visit, exam or consult
	17. Combination
	18. Non-specified
	19. Other (write in)
	20. Medication, Antibiotics

III SPECIFIC INTERVENTIONS

NARCOTICS	1.	Morphine sulfate
	2.	Dilaudid
	3.	Phenobarb
	4.	Demoral
	5.	Other narcotic (write in)
CHEMOTHERAPY	10.	Adriamycin, doxorubicin
	11.	Cisplatin, plantinol
	12.	Mitomycin, mutamycin
	13.	Floxuridine, FUDR
	14.	Cyclophosphamide, cytoxan, neosar, nitrogen mustard, mechlorethamine
	15.	Carmustine, BICNO, bisochlorethyl
	16.	Lomustine, CeeNU
	17.	Methotrexate, mexate, folex
	18.	Fluorouracil, adrucil
	19.	Other chemotherapeutic agent (write in)
GENERAL MEDS	20.	AZT
	21.	Pentamidine
	22.	Aminophylline
	23.	Heparin
	24.	Polypharmacy (multiple)
	25.	Other general medication specified (write in)
	230.	Valium
	231.	Haldol
	232.	Solucortef
	233.	Sodumedrol
	234.	Sandostatin
	235.	Dilantin
	236.	Zantac
	237.	Reglan
	238.	Ativan
	239.	Potassium
	240.	Compazine
	241.	Laoix
	242.	DHPG
	243.	Decadron
BLOODS	30.	Packed cells
	31.	Platelets
	32.	Fresh frozen plasma
	33.	Albumin
	34	Other blood product (write in)

III SPECIFIC INTERVENTIONS (CONTINUED)

SUPPLIES	40.	Supplies, IV
	41.	Supplies, respiratory
	42.	Supplies dialysis
	43.	Other supplies (write in)
	44.	Feeding Tube peg, NG, DopHoff
	45.	NG Suction, Gastric, Suction Equipment
EQUIPMENT	50.	IV pump
	51.	Ventilator
	52.	Bed
	53.	Other equipment (write in)
	54.	PCA Pump
	55.	Cadd Pump
	56.	Implantable Pumps
	57.	Feeding Pump
	58.	Service/maintainence
	59.	Equipment rental
TPN	60.	Total parenteral nutrition, amino acid only
	61.	Total parenteral nutrition, carbohydrates only
	62.	Lipids
	63.	Total parenteral nutrition amino acid and carbohydrates
	64.	Other TPN (write in)
ENTERAL FEEDS	70.	Pulmocare, isocal, ensure, ensure HN, ensure powder, lonalac, meritene, meritene powder
	71.	Compleat B, vitaneed, compleat B modified
	72.	Magnecal, isocal HCN, sustacal, HC, ensure plus, ensure plus HN
	73.	Criticare HN, vital TEN, vital HN, travasorb HN, isotrin HN precision NH
	74.	Hepatic and, travasorb hepatic, travasorb MCT, travasorb renal
	75.	ProPAC, gerval protein, casec, moducal controlyte, polycase
	77.	Vivonex STD, travasorb standard, precision LR, tolerex
	78.	Other enteral feeding (write in)
	79.	Osmolite

III SPECIFIC INTERVENTIONS (CONTINUED)

PROCEDURES

(Radiology)
100. X-ray
101. Bone scan
102. Magnetic resonance imaging
103. Venogram
104. Computerized tomography
105. Ultrasound
106. Other radiological procedure (write in)

(Surgery)
110. Hip reduction/fracture
111. Tracheostomy
112. Lumbar puncture
113. Placement of Broviac, Hickman, epidural or central catheter-subclavian or jugular
114. Placement of gastrostomy,jejunostomy tube
115. Placement of dophoff, nasogastric
116. Placement of intraspinal catheter
117. Placement of implantable infusion pump
118. Biopsy
119. Other surgical procedure (write in)

(Cardiovascular)
120. Doppler testing
121. Echocardiogram
122. Electrocardiogram
123. Cardiopulmonary resuscitation
124. Other CV procedure (write in)

(Respiratory)
130. Bronchoscopy
131. Thoracentesis
132. Chest tube insertion
134. Intubation
135. Other respiratory procedure (write in)

(G/I)
140. Upper GI
141. Barium Enema
142. Paracentesis
143. Endoscopy
144. Other G/I procedure (write in)

(Urinary)
150. Dialysis
151. Other Urological procedure (write in)

(Lab)
160 Blood culture
161. Urinalysis
162. Complete blood profile
163. Electrolyte screen - 7 panel
164. Electrolyte screen - 12 panel

III SPECIFIC INTERVENTIONS (CONTINUED)

PROCEDURES (con't.)

(Labs con't.)	165. Prothrombin time
	166. Cytology
	167. Other laboratory procedure (write in)
	168. Digoxin
	169. Dilantin
	170. Theophylline
	184. Wound Culture
(Other)	182. ER Visit
	183. EEG
NURSING	171. Nursing non-continuous visits
	172. Nursing continuous care
THERAPY	330. Physical Therapy
	331. Social Work
	332. Occupational Therapy
	334. Pastoral
PHYSICIAN	335. Visit
	336. Exam
	337. Consult
ANTIBIOTICS	190. Ancef
	191. Bactim
	192. Cefobid
	193. Cleocin
	194. Ceftriaxone
	195. Erythromycin
	196. Flagyl
	197. Fortaz
	198. Pencillin
	199. Pipercillin
	200. Septra
	201. Vancomycin
	202. Other antiobiotic (write-in)
	210. Ampicillin
	211. Gentamycin
	212. Mezlocillin
	213. Unasyn
	214. Zinacef
	215. Naficillin
	216. Emycin
	217. Cefoxitin
	218. Kefzol

III SPECIFIC INTERVENTIONS

ANTIOBIOTICS (con't)

219. Cipro
220. Amikacin
221. Tobramycin
222. Ticarcillin

OTHER

180. Combination
181. Other type of intervention (write in)

IV UNIT OF MEASURE

1. Days
2. Treatment
3. Procedure
4. Course
5. Visit
6. Medication
7. Hospitalization
9. Other (write in)
10. Supplies

V DOSE

VI ROUTE OF ADMINISTRATION

1. Intravenous continuous, external pump
2. Intravenous non-continuous
3. Oral
4. Intramuscular
5. NG, Dophoff
6. Gastric, Jejunostomy
7. Subcutaneous
8. Intravenous continuous, implanted pump
9. Intraspinal
10. Epidural
11. Other (write in)

VII FREQUENCY

VIII COSTS

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